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ABSTRACT

The project sought to determine the content and form of materials that would enable parents of children with disabilities to become informed critical consumers of respite services. Project activities included establishment and utilization of a national advisory panel; an indepth review of the literature on family supports, systems change, and consumer empowerment; and a national survey of parents. The literature review found that respite literature is focused on establishing and maintaining respite services, with few evaluation studies or resource guides. Respite literature is primarily directed at providers. The national survey was shrink-wrapped with the October 1988 issue of "Exceptional Parent Magazine," which was distributed to some 22,943 subscribers; of these, 2,847 sent back completed and usable forms for a return rate of 12.41 percent. The survey covered: description of the family member with a disability; description of the household and caregiver; availability and use of respite; satisfaction with respite; problems with respite; desirable information and most preferred form for information; and desirable forms of family support services. The study concludes that respite is a valuable resource for families who are able to utilize it; however, families seem to have substantial problems working out the details of obtaining necessary support. Implications of the study for developing training materials are outlined. The report concludes with 11 references, a list of 6 resources on respite care, a list of members of the project advisory panel, and a copy of the survey questionnaire. (JDD)

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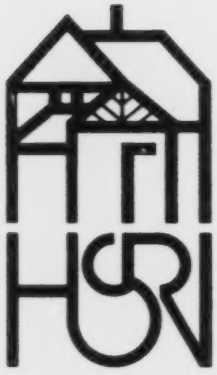
BECOMING INFORMED CONSUMERS:

A NATIONAL SURVEY OF PARENTS' EXPERIENCE WITH RESPITE SERVICES



HUMAN SERVICES RESEARCH INSTITUTE

EC 232134

FINAL PROJECT REPORT

DEPARTMENT OF EDUCATION

CONTRACT NUMBER: RS88072003
Guide Materials for Respite Care for Families with Members Who Are Disabled

BECOMING INFORMED CONSUMERS: A NATIONAL SURVEY OF PARENTS' EXPERIENCE WITH RESPITE SERVICES

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Introduction

"Respite" is the blanket term used to describe a wide range of services for families who care for a child with a developmental disability or serious medical condition at home. Its origins are found in efforts to give parents some "relief," some respite, from the day-to-day demands of caring for a child with a disability. As it has evolved over the last decade respite has come to mean **any service or program which provides care for a person with a disability while the primary care giver is engaged in some other activity**. Under this expansive umbrella, all of the following situations can be found and more.

- Beds in a mental retardation institution can be periodically reserved by parents. These same places are also available if a crisis arises which impairs the family's ability to care for its member with a disability.
- Spaces in local group homes for people with disabilities can serve the same function as institutional programs.
- A variant of these institution and group home based programs is a system whereby individual families take turns using respite facilities according to a pre-set schedule. Family members must confirm these dates at the beginning of the year or loose them.
- A respite house or center is a group home serving exclusively as a respite facility. Usually such programs allow parents to schedule specific periods of time, up to two full weeks, in advance. They also provide emergency respite so that a child living at home does not have to go into an institution during a family crisis.
- A licensed respite provider will take a person with a disability into his or her home for any prearranged period of time ranging from a few hours to a week.
- A respite agency will arrange for its employees to care for the person with a disability either in the family home or the provider's home.
- A Licensed Practical Nurse may be sent by a home health care agency on a weekly basis to provide "respite" for a child with severe disabilities while the parent does the family's grocery shopping.

- A "regular" day care center may accept children with disabilities.
- A neighborhood center's after-school program provides special staffing so that each of its activity groups can include one child with severe disabilities.
- A neighbor, recruited and trained by the family itself, is certified by a state agency as a respite provider for that family.
- A drop-in weekend day center with limited space offers respite care for children with disabilities on a first come, first served basis.
- A college student spends three hours every afternoon after school with a young man with autism enabling both of his parents to retain their full time jobs.

Listing all of these possibilities together creates the illusion of a comprehensive system of respite services which should be sensitive to meeting any need a family may have. While a survey of services across the nation is able to identify individual instances of just about any type of respite a family may desire, the reality is that in most areas families have few, if any, alternatives. If respite services exist, they are likely to be limited to one or two possibilities which are presented to families on a take it or leave it basis.

For some parents the options presented by such services are not really viable. For example, when presented with the need to place a child with severe disabilities in an institution in order to be able to take a weekend trip, many parents will forego the trip. More affluent families may hire an LPN at $25.00 an hour, but that is not a choice that many families can afford to make.

The approaches to funding respite services are almost as diverse as the services themselves. In areas of the country where there is little public support for respite care, families and not-for-profit agencies must carry most of the cost. On

the other extreme, there are states which provide families with cash support, a certain amount of pre-paid free respite, and publicly subsidized services which are available to families at a greatly reduced cost should they use up their allotted amount of respite (e.g., Michigan). Between these extremes there is a wide range of funding mechanisms. These include partially subsidized private services, public agencies with a co-payment provisions, voucher systems, and systems where the public contribution is negotiated between the family and the case manager on an individual, as-needed basis.

This tremendous diversity in respite services results from the fact that these services are only now finding their form. The uncertain nature of this development process mirrors the changing public policy environment in which it is occurring.

Less than 20 years ago the only publicly funded support available to a family who had a child with a disability was institutionalization. Since then, the public outcry against the abuse so often associated with institutional life and an awareness of the trauma inflicted on families in the name of helping them has fostered a rejection of institutionalization as a mode of service for children with developmental disabilities. Moreover, there is increasing recognition that the great majority of families reject out-of-home alternatives in favor of continued care at home, especially during the child's early years. Taken together, these circumstances have prompted a deepening concern that families and their members with disabilities receive the supports they need.

As a result, the newer models of service emerging over the last 15 years are presented as being "family-centered" and "community-based". In reality, most state and local systems are only beginning to come to grips with the implications of this kind of rhetoric. Public policy is actively seeking to define the most useful role the public sector can play in assisting families to care for children, including those with the most severe disabilities, at home. States pay over $100.00 a day to support a child in an institution while still questioning the advisability of programs which provide in-home supports to families. As the focus shifts, the not infrequently asked question is "Should the public sector pay parents to care for their own children?"

Parents of children with disabilities need to take an active role in these policy discussions which so directly affect their lives. They must be able to define their own vision of what they need and communicate that vision to their representatives. On the local level, parents need to be active participants in the development and evaluation of the services they actually receive. Only then can they be assured of the appropriateness and quality of these services.

Parents and other primary care providers are faced with the need to be informed, intelligent, and active consumers of respite services. But given the day-to-day demands of caring for a child with a disability, where can they turn for the information they need to fulfill this role?

PROJECT OBJECTIVES

Using information gathered from a survey of family members and from a literature review, this project seeks to determine the content and form of materials

that will enable parents to become informed critical consumers of respite services. A complementary aspect of this project, that is inseparable from this central intent, views the focus on respite issues as providing a forum that enables parents to develop the skills to be effective advocates for themselves and their children in all domains of life.

The objectives of this project are intended to lay the groundwork for developing a range of materials that will provide parents with the information they need to take a formative role in the area of family supports and respite services in particular. In keeping with this focus on empowerment, project activities outlined here called on parents of children with disabilities to inform our efforts. We needed them to tell us what they already know, what they need to know, and the most effective ways of getting the products of this project back to parents. The project entailed three major activities which are addressed in the subsequent sections of this report.

1. Establishment and utilization of a **national advisory panel** made up of parents of children with developmental disabilities, chronic illness, severe physical disabilities, and emotional disturbance as well as professionals with expertise related to these disabilities and respite services.

2. An indepth **review of the literature** on family supports, systems change, and consumer empowerment as it relates to respite services for people with disabilities and their families with the primary aim of identifying materials which can be translated into practical resources for family members.

3. **A national survey of parents** who are caring for children with severe physical disabilities, chronic illness, emotional disturbance, and developmental disabilities at home to determine a) their experience with respite services, b) their perception of what they need to know to be more effective consumers of respite services, c) their perception of the need for additional services to meet the needs of their child and family, and d) the form materials should take in order to be most accessible to them.

Project Advisory Panel

To assure that the family-centered focus of this project did not become lost, an initial project activity was the recruitment of a national advisory panel, the majority (10) of which are parents of children with disabilities. Four members of the board are professionals with expertises in research, education, and/or respite services. The full advisory group has 15 members (see Appendix 1). This group acted as a review board for all of the project activities. The specific tasks of this board included:

- o reviewing and commenting on all project survey instruments or interview protocols,
- o reviewing and commenting on the drafts of all project reports,
- o nominating model respite programs and model service systems from around the nation,
- o nominating knowledgeable professionals, and
- o identifying materials that are particularly helpful to parents.

Several sources were used to recruit members for the advisory panel. The editors and editorial board of *Exceptional Parent Magazine* were asked to nominate both professional and parent members. Through its relationship with Human Services Research Institute, HSG has direct access to The Advocacy Liaison Network. This coalition of several major disability related advocacy organizations was recently established by United Cerebral Palsy Associations, in part, to consider issues pertaining to family supports. Among the members of this coalition are representatives of The Association for Retarded Citizens (ARC/US),

the Association for Persons with Severe Handicaps (TASH), United Cerebral Palsy Association (UCPA), The Association for the Care of Children's Health (ACCH), SKIP (Sick Kids Need Involved People), the Autism Society of America, and the Mental Health Association. Representatives of this group were asked to nominate members for the advisory board of this project. In addition, based on our review of the literature, we approached professionals who are knowledgeable in the areas of respite, family supports, and parent organizing to serve on the board.

Literature Review

To assess the types of materials that are available to consumers of respite care, a comprehensive review of the literature was undertaken. This review does not attempt to evaluate the content or quality of the works cited but rather to characterize the nature of existing documents on respite care services and their stance toward parents as consumers.

METHOD

Three databases -- ERIC which covers educational materials, Nursing and Allied Health and PSYCINFO which covers psychology and related behavioral sciences -- were searched by the keyword "respite." The ERIC database produced 94 entries and all were used. The nursing database provided 47 entries but only 11 were used for this review. Some entries were duplicative but most entries addressed respite care for gerontology patients in a hospital setting. This literature was not considered to be appropriate for inclusion in this review. The PSYCINFO database had 15 respite cites and 13 were used. The two cites which were not used referred to respite care in only an indirect context. Annotated bibliographies on respite care and other related fields (i.e., attendant services, home care, family support) were reviewed as well as primary sources.

In an effort to determine the nature of the existing respite literature, 170 materials were classified into six descriptive categories. These descriptive categories were developed after an initial screening of the literature. They were designed such that together the categories would provide a comprehensive

framework for the body of respite literature. Each reference material was classified into one and only one of the following categories.

1. *Types and Models.* This heading primarily includes literature which describes model programs or defines types of respite services or lists available resources. In many cases, these works include extensive information on the development of respite services as well. They were categorized here instead of in the development category because they are descriptive as opposed to "hands on" or "how to" materials. Evaluations of model programs and materials which describe policy options are also found in this category.

2. *Development.* All materials which relate to the actual development of respite care programs are included under this heading. In general, these are "how to" resources. Documents which detail the historical development of respite were also placed here.

3. *Training Materials.* This category covers all materials related to the training of respite providers including babysitters, nurses, volunteers, etc. Materials evaluating or reviewing training options were also included here.

4. *Impact on Quality of Life.* In addition to literature which documents the impact respite services have on the quality of life for children and families, studies which evaluated consumer satisfaction and documented parents' perceptions of respite care were also included.

5. *Need For Respite Services.* This category covers all materials documenting the need for respite services including surveys which address parents' perceived need for respite care.

6. *Other.* A few materials were difficult to place in any of the above categories. These include state plans on family support that partially address respite services, evaluations that document the present state of respite services in general, works that provide simple overviews of the field of respite care, studies that define who respite users are, and one article that deals exclusively with parents' role as respite consumers.

There is a comprehensive bibliography of respite training and/or development manuals by state (Texas Respite Resource Network, undated). The materials found in this bibliography were not included in this classification of literature. It

was determined that the inclusion of many reports from such a selective document would seriously misrepresent the nature of the immediately available literature on respite care. The fact that most respite programs do have some documented training materials does not accurately reflect the type of literature a consumer will find when going to the library.

In addition to classifying all materials into one of the above areas, a count was made of materials that primarily addressed one of the following selected topics.

1. *Rural Respite Services.* Materials deal with the particular issue of obtaining respite care in rural areas.

2. *Institutional Respite Services.* All materials that address respite services as provided by institutions were included here.

3. *Adult Respite Care.* All materials that are concerned primarily with providing respite services to families caring for adult members with disabilities were counted in this category. However, as discussed above, there are many materials that address providing geriatric respite in hospitals. It was determined that many of these services are substantively different than respite care to families with children with disabilities and hence were not included.

4. *Cross Cultural.* This heading covers any material that looks at respite care in other countries.

5. *Funding Opportunities.* Materials primarily discuss funding options, resources and opportunities.

6. *Resource Guides.* Literature is included that specifically lists available respite services in a given area.

Occasionally the same material was listed under two selected topic headings. For example, a study of respite services in rural areas for care givers of adult family members would be counted under both rural and adult headings.

RESPITE CARE LITERATURE REVIEW

TABLE 1A

CLASSIFICATION OF MATERIALS		# OF VOLUMES FOUND	PERCENT OF TOTAL (170)
TYPES/MODELS OF RESPITE SERVICES		63	37.1%
PARENTS AS PROVIDERS	7		
PROFESSIONALS AS PROVIDER	56		
DEVELOPMENT OF RESPITE SERVICES		28	16.5%
PARENT INITIATED	6		
OTHER INITIATED	22		
TRAINING MATERIALS		13 **	7.6%
IMPACT ON QUALITY OF LIFE		20	11.8%
NEED FOR RESPITE SERVICES		33	19.4%
OTHER -- RESOURCE GUIDES, REVIEWS, ETC		13	7.6%
TOTAL NUMBER OF MATERIALS REVIEWED		170	

(** A bibliography of training and development manuals (TRRN, undated) was reviewed but not included in this breakdown. This bibliography provided a respite resource for most states. Inclusion of this work would greatly increase the development and training categories. It was determined that such a selective bibliography would misrepresent the literature at large.)

TABLE 1B
(OF 170 REVIEWED, NUMBER OF RESOURCES THAT ADDRESSED THESE TOPICS IN DEPTH)

SELECTED TOPICS	# OF VOLUMES FOUND	PERCENT OF TOTAL (170)
RURAL ACCESS TO RESPITE SERVICES	5	2.94%
INSTITUTIONAL RESPITE	4	2.35%
RESPITE SERVICES FOR ADULT FAMILY MEMBERS	22	12.94%
CROSS CULTURAL RESPITE STUDIES	9	5.29%
FUNDING OPPORTUNITIES	7	4.12%
SPECIFIC LISTING OF AVAILABLE RESPITE SVCS	5	2.94%

(Some materials are represented in more than one category, e.g. adult repite services in Britian)

RESULTS

As shown in Table 1A, thirty-seven percent of the respite literature describes the types of respite available and/or existing model programs. The next largest segment (19.4%) of the literature documents the need for respite services and a nearly equal amount of literature discusses the process of developing respite care programs. Nearly 12% of the literature looks at the impact that respite services have on the quality of life of the people served. While training materials represent the smallest portion of the literature (7.6%), it should be born in mind that many training materials were omitted from this review. While training manuals may not often be found in the local library, they do seem to be plentiful and readily available as was the experience in this project's efforts to secure them.

Conspicuously missing from or underrepresented in the literature are the types of materials which were categorized as "Other." Only one article is specifically geared to parents and the ways that they can have input into *existing* respite services. Only two reports exclusively focus on who the users of respite are. There are only five materials which take broad overviews or evaluate the status of respite services in general or in a given state.

In Table 1A, the categories of Types/Models and Development show a breakdown of materials within these categories based on a parent versus provider emphasis. In Development, materials were determined to be parent initiated if they addressed programs such as family coops where parents take turns caring for one another's children. Under Types/Models, the parents as providers subsection represents materials which address these models as well as volunteer families. It should be noted that these are fairly rough categorizations. Much of the literature

discusses a variety of program types. If both professional initiated and parent initiated programs are covered by a report, the material was classified as professional.

Table 1B shows that small segments of the literature address institutional respite care (2.3%), respite services in rural areas (2.9%), and resource guides for existing respite services in a given area (2.9%). However, in regard to resource guides, some of the Model/Type, Development and Training literature does contain appendices that can direct readers to existing programs. Materials that primarily address funding issues and options compose 4.1% of the works reviewed. Cross cultural studies make up a slightly larger portion of the literature (5.3%). Respite care that addresses the needs of adult family members with disabilities or aging parents makes up nearly 13% of the literature. Many of these latter materials also addressed the needs of families with children with disabilities as well.

ANALYSIS

The literature of a given field can be thought of as reflecting the developmental phase of that field. The respite literature mirrors the youth of the respite field. In creating new programs, first one must document need. There is a sizable amount of respite material on this subject. Then one must establish and publicize pilot programs and promulgate new models. The bulk of the respite literature is found in this descriptive category of Types/Models. Then one must develop tools for replicating these programs. There is a smaller but substantial amount of work in the "hands on" Development category. Training materials are also a part of this process. While this review shows few actual training materials, the process of this review found that training materials are readily available and

had they all been included would have overwhelmed the other categories. In the later stages of program development, issues such as evaluation, demonstration of the impact of services, analysis of long term program effects and re-evaluation of existing models take precedence. There is not an abundance of literature on these topics. Currently, the field of respite care is still establishing itself by cultivating and disseminating materials on model programs, service options, and replication strategies.

The small numbers of materials found under some of the selected topics also seem to reflect the relative newness of the field. There are surprisingly few descriptions of existing services and few works that look at overall funding strategies. While not specifically tallied, very few works seem to focus on larger policy issues or systemic concerns.

The developmental stage of respite services is also reflected in the character of the literature as well. Much of the literature, regardless of classification, begins by detailing the forms that respite care can take and eventually discusses methods of implementation. Materials are generally aimed at providers in the field who might choose to establish programs. The literature rarely speaks to parents directly. Materials that do address parents are typically providing them with information on how to set up a parent initiated respite program.

It is not that parents are unconsidered in the literature. Many issues are addressed including the importance of carefully matching parents and respite providers, ways to involve parents in new respite care, and parent evaluation of received respite services. Again, however, most of these works address the ways in

which providers can and should include parents. The available material does not focus on parents and their need to become informed consumers of services.

This fact is further highlighted when respite literature is compared to a bibliography of literature on personal assistance services and independent living. (Nosek, et al, 1988). A sizable portion of personal assistance literature addresses the management and use of personal attendants from the perspective of the consumer. There are materials aimed specifically at making the users of personal assistance services effective and capable managers of their attendants. This stands in sharp contrast to the materials in the respite field which do not, as yet, address these kinds of issues.

SUMMARY

In general, the respite literature is focused on establishing and maintaining respite services. There are surprisingly few evaluation studies or guides to resources -- what might be termed "after the fact" documents -- materials that assume the existence of services. Respite materials are primarily directed at providers -- those who will create respite services. When the literature is aimed at parents, it usually views them as actually establishing a respite care program.

Here in lies the inherent contradiction in the respite literature. Parents seek respite because they need more time yet sometimes they are called on by professional authors to become the providers for the very service they need. While establishing a respite program would have long term benefits, it would be surprising if many of these parent have the time needed for start up activities. Materials do not articulate a way for parents to be involved in the start up of a

respite program while minimizing the time commitment and maximizing their input into the shape of the service. There is not much literature on what parents can expect and request from respite care programs. There is no literature on the ways parents can insure that respite care meets their needs. The existing literature addresses the need for providers to match respite workers with families but not how families should choose a respite worker.

Many of the development materials describe how difficult it is for new programs to get families to trust them and to participate. This trust might be more forthcoming if parents were taught to be competent and capable consumers, and felt truly in control of the services that affect their lives.

National Survey

METHOD

This survey was designed as a way to listen to families and to develop a profile, now largely lacking, of what their experience of respite has been and what they need to know to improve this experience. The potential results of this effort would be two fold 1) to develop material which will assist parents to be come empowered consumers of respite services and 2) to contribute to the national base of information and thus ensure that the voice of parents is heard in the formulation of policy and the design of services.

Instrument

To achieve this goal, a 46 item questionnaire was designed (see Appendix 2). The majority of the items on this form were forced choice and Likert rating scales. Several fill in the blank items were also included in the survey. These latter items usually solicited the number of hours of service available and used or the cost of services. The survey was divided into 7 major sections: 1) description of the family member with a disability; 2) description of the household and care giver; 3) availability and use of respite; 4) satisfaction with respite; 5) problems with respite; 6) desirable information and most preferred form for information; and 7) desirable forms of family support services.

A final item asked respondents to indicate if they would be willing to be contacted later for an interview which would follow up on their survey answers. They indicated willingness to participate in this interview by supplying their

name, address, and phone number. Almost 82% of all respondents expressed a willingness to be contacted later.

Because of the limited time available for this project (6 months) it was not possible to field test the survey form. This limitation of the project methodology was taken into account by selecting parent members for the advisory panel who represent geographic diversity and diverse experiences related to the disability of their child. In selecting professional members of the advisory panel care was taken to insure that these individuals were familiar with issues of research and respite. A draft of the survey was distributed to the project advisory panel and substantially revised based on their recommendations.

Subjects

The participation of *Exceptional Parent Magazine* afforded this project a unique opportunity to achieve its goal of sampling widely from the national experience of parents with respite services. *Exceptional Parent* is a national forum for the exchange of information among parents of children with disabilities. It has consistently championed the cause of parental and family empowerment and promoted the view that parents are the real experts when it comes to their children.

Exceptional Parent was started in 1971 by Maxwell J. Schleifer, Ph.D. and Stanley D. Klein, Ph.D.. Exceptional Parent Press published its first book in 1975. Recently, it published its sixth book and several additional volumes are in production and are expected to be published this year. *Exceptional Parent Magazine* and its books have retained the original goal of providing practical

information and support for parents in understandable language. This information on the care and education of children with disabilities can help parents take greater charge of their own and their children's destiny. The goals and values of this organization as well as it publishing capabilities are ideally suited to realizing the overall objectives of this project.

With more than 20,000 paid subscribers throughout the United States, *Exceptional Parent* provides a unique entre into the home of the readers. Reader surveys show that most *Exceptional Parent* subscribers read the magazine cover to cover, including advertising, and that the readers feel a strong bond with the magazine and its editors. This indicates that readers would be aware of the survey questionnaire and increases the likelihood that many would complete it. Reader surveys also indicate that most readers of *Exceptional Parent* are well educated, upper income families whose children have relatively severe disabilities, chronic illnesses, and/or mental retardation.

The respite survey was shrink-wrapped with the October 1988 issue of *Exceptional Parent Magazine*. A pre-paid return mail envelop was attached to the form. This mode of distribution insured that the form would not be missed by subscribers -- it was the first thing they saw on receiving their periodical. The form had a cover letter from the editors explaining the purpose of the survey. This was reiterated in the editor's column inside the magazine. The October issue had a distribution of 22,943 copies. This issue was received by all subscribers by mid October. The November issue of the magazine carried a prominent reminder to subscribers to return the completed surveys. December 12, 1988 was the final return date for all usable questionnaires. By that date, 2,847 completed and

useable forms were received. This represents a return rate of 12.41%, an excellent showing for an unsolicited mailing.

RESULTS

Respondents

From the outset, it was understood that this survey would not produce a sample which was completely representative of families caring for a member with a disability. This limitation was inherent in chosing *Exceptional Parent* and was discussed with the editors at the very beginning of the project. It was determined that the advantages to be gained by building on the good will which the subscribers have toward this publication more than outweighed any limits on generalizability.

As anticipated, the responses to the survey mirror the demographics of the *Exceptional Parent* mailing list. What emerges from the sample is a picture of a relatively prosperous, well educated, informed, and sophisticated group. While there remains a challenge to gain parallel information from people in lower socio-economic strata, this sample presents certain advantages. The socio-economic indicators, outlined below, and the very fact that this sample subscribes to the premier publication for informing parents of children with disabilities leads us to expect that we should be in touch with the most informed and empowered parents. From this group we would expect to see the highest possible level of knowledge and control as it relates to the services for their child and family. In this regard, they should be able to act as something of a standard of service system sophistication against which to gauge other groups of parents.

Household Characteristics

In a time when most discussions related to child care and family supports are prefaced by the caveat that all efforts must be sensitive to the changing nature of the family, our sample seems to represent a consistent picture of the "normative" two parent household. Table 2 summarizes the characteristics of the sample households. It should be pointed out that the list of primary descriptors for the household ("two parent," "single parent" "foster home," "shared household,") were not mutually exclusive. More than 85% of the respondents identified their household as having "two parents in the home." The average household had 4.12 people. The average number of children in a household was 2.57 (range 0 (n=186) to 17 (n=1)).

A majority of the households are supported by a single income (69.2%, n=1970). Of the households sampled 19.5% have more than 1 full time income and approximately 32% obtain some part of the household income from part time employment. Table 3 presents a summary of the household income levels. 62.4% of the respondents report a 1987 taxable income in excess of $30,000.00.

The vast majority of the returned questionnaires were completed by the mother of the person with a disability (n=2483, 87.2%). In most cases, the mother is also the primary care giver (see Table 4). It is interesting that although the father is the primary care giver in only 1.9% (n=54) of the cases, in more than twice that many cases (4.9% (n=140)) the father was the individual responsible for completing the survey questionnaire.

TABLE 2

CHARACTERISTICS OF HOUSEHOLDS RESPONDING TO RESPITE SURVEY

CHARACTERISTIC	PERCENT OF HOUSEHOLDS
TWO PARENTS	85.2%
SINGLE PARENT	11.5%
FOSTER HOME	2.3%
LIVING WITH RELATIVES	2.0%
SHARED HOUSEHOLD	1.5%
OTHER ARRANGEMENTS	5.7%
SIZE OF HOUSEHOLD:	
2 PERSONS	6.1%
3 PERSONS	25.0%
4 PERSONS	38.7%
5 PERSONS	19.2%
6 PERSONS	7.0%
>6 PERSONS	4.0%
NUMBER OF PEOPLE EMPLOYED FULL TIME:	
0	3.9%
1	69.2%
2	18.3%
3	0.9%
4	0.2%
NO RESPONSE	7.3%
PART TIME:	
0	15.9%
1	29.8%
2	2.7%
3	0.2%
4	0.1%
NO RESPONSE	51.1%

TABLE 3

ANNUAL INCOME OF
HOUSEHOLDS RESPONDING TO RESPITE SURVEY

1987 TAXABLE INCOME	PERCENT OF HOUSEHOLDS
$0-$9999.00	5.9%
$10,000.00-$19,999.00	12.1%
$20,000.00-$29,999.00	19.6%
$30,000.00-$39,999.00	19.3%
$40,000.00-$49,999.00	17.0%
$50,000.00-$75,000.00	18.1%
>$75,000.00	8.0%

TABLE 4

PRIME CARE GIVERS IN
HOUSEHOLDS RESPONDING TO RESPITE SURVEY

CARE GIVER	PERCENT OF HOUSEHOLDS
MOTHER	94.1%
FATHER	1.9%
SIBLING	0.1%
AUNT/UNCLE	0.3%
GRANDPARENT	0.4%
OTHER	2.5%

The level of education of the primary care giver and any other adult in the household presents another measure which differentiates the survey sample from a random national sample (see Table 5). This sample group is very well educated -- 50.1% of the primary care givers and 54% of other adults have at least a college degree with over 26% of the other adults having some graduate education.

The information contained in Table 6 presents a telling supplement to the data on household incomes and level of education. With the high level of education observed, we anticipate seeing larger numbers of two income households. When the respondents were asked to identify some of the opportunity cost associated with care of the family members with a disability, the data reveal that this probably would have been a realistic expectation if someone in the family had not had a disability. Over 46% of the households report that someone has not pursued employment or education because of the demands of care. In 35.5% of cases a member of the household has actually given up employment because of the presence of a family member with a disability. Additionally, a substantial number of households report that the need to be concerned about care for a person with a disability has influenced some aspect of a family member's employment experience.

Family Members with a Disability

The family members with disabilities in our responding households ranged in age from under 1 to 86 years of age. Table 7 provides a summary of the age distribution of this sample. The average person was a child 8.8 years of age. Only 8.5% (n=282) of the sample was over 18 years old.

TABLE 5

EDUCATIONAL LEVEL OF PRIME CARE GIVERS IN HOUSEHOLDS RESPONDING TO RESPITE SURVEY

LEVEL OF EDUCATION	PERCENT OF CARE GIVERS
GRADE 8	9.0%
HIGH SCHOOL	20.8%
SOME COLLEGE	28.2%
COLLEGE GRAD	30.1%
GRAD SCHOOL	11.4%
ADVANCED DEGREE	8.6%

EDUCATIONAL LEVEL OF SECOND ADULT IN HOUSEHOLDS RESPONDING TO RESPITE SURVEY

LEVEL OF EDUCATION	PERCENT OF OTHER ADULTS
GRADE 8	1.8%
HIGH SCHOOL	21.2%
SOME COLLEGE	23.0%
COLLEGE GRAD	27.6%
GRAD SCHOOL	11.9%
ADVANCED DEGREE	14.5%

TABLE 6

OPPORTUNITY COSTS REPORTED BY HOUSEHOLDS RESPONDING TO RESPITE SURVEY

A MEMBER OF THE HOUSEHOLD HAS...	PERCENT OF HOUSEHOLDS
NOT PURSUED FURTHER EDUCATION	46.8%
NOT PURSUED EMPLOYMENT	46.3%
GIVEN UP EMPLOYMENT	35.5%
CHANGED JOB FOR DIFFERENT HOURS	27.5%
REFUSED TRANSFER OR PROMOTION	20.9%
CHANGED JOB FOR BENEFITS	17.1%

IN ORDER TO TAKE CARE OF THE FAMILY MEMBER WITH A DISABILITY

TABLE 7

AGE DISTRIBUTION OF FAMILY MEMBERS WITH DISABILITIES

AGE RANGE	PERCENT OF SAMPLE
<3	12.90%
3-5	27.30%
6-10	30.10%
11-15	15.40%
16-18	5.80%
>18	8.50%

MEAN AGE 8.8 YEARS
MEDIAN AGE 7 YEARS
MODE 5 YEARS

The majority of the sample described their family member as having more than one condition that could be characterized as "disabling." Table 8 synthesizes this information on conditions. The first row in the table presents the total number of cases in which a particular type of condition was identified. The diagonal created by the end of each row contains the number of times a particular condition was selected as the only disability. The remaining rows and columns indicate the number of cases in which the two conditions that intersect were both selected by the respondents. The bottom of the table, entitled "summary," presents the frequency with which respondents used the range of multiple conditions (1-8) to describe their family member.

Of greater interest than the frequency with which a type of disability was identified is the measure of the severity of that condition. Our respondents were asked to rate four classes of disability (intellectual, physical, medical, behavioral) on a four level severity scale. These data are presented in Table 9. On this scale "slight" indicates that this type of condition was essentially not a problem for the family member with a disability. The sample indicates, on average, more severe intellectual and physical disabilities and somewhat less serious medical and behavioral problems. 74.7% of the sample indicated moderate to severe intellectual disability and 65.6% identified the same range of physical disability. As far as medical involvement was concerned, 32.1% of the sample saw their family member as having a moderate to severe level of need. In the area of behavior problems, 31.9% of the sample report moderate and severe conditions but the majority (25.9%) report moderate levels of disability. A summary score was developed to gain a measure of each household's overall level of disability across

TABLE 8

SUMMARY OF DISABLING CONDITIONS REPORTED BY SURVEY RESPONDENTS

	MEDICAL CONDITION	PHYSICAL DISABILITY	DEVELOPMENTAL DISABILITY	SPEECH IMPAIRMENT	HEARING IMPAIRMENT	VISUAL IMPAIRMENT	EMOTIONAL DISTURBANCE	OTHER
TOTAL	1120	1733	2197	1477	324	699	422	635
MEDICAL	16							
PHYSICAL	875	168						
DEVELOPMENTAL	967	1305	278					
SPEECH	753	1093	1316	4				
HEARING	173	228	280	234	8			
VISUAL	402	589	622	501	160	5		
EMOTIONAL	186	199	368	281	64	102	15	
OTHER	214	305	429	305	77	142	106	103
SUMMARY:	597 RESPONDENTS IDENTIFIED 1 CONDITION	562 RESPONDENTS IDENTIFIED 2 CONDITIONS	570 RESPONDENTS IDENTIFIED 3 CONDITIONS	558 RESPONDENTS IDENTIFIED 4 CONDITIONS	367 RESPONDENTS IDENTIFIED 5 CONDITIONS	123 RESPONDENTS IDENTIFIED 6 CONDITIONS	45 RESPONDENTS IDENTIFIED 7 CONDITIONS	7 RESPONDENTS IDENTIFIED 8 CONDITIONS

TABLE 9

PERCENT OF FAMILY MEMBERS AT VARIOUS LEVELS OF DISABILITY

TYPE OF DISABILITY	SLIGHT	MILD	MODERATE	SEVERE
INTELLECTUAL	8.0%	17.2%	33.6%	41.1%
PHYSICAL	11.9%	22.4%	22.8%	42.8%
MEDICAL	17.4%	50.6%	6.5%	25.4%
BEHAVIORAL	42.5%	25.4%	25.9%	6.2%
OVERALL	1.1%	30.1%	44.00%	24.8%

TABLE 10

PERCENT OF FAMILY MEMBERS WITH DISABILITIES NEEDING ASSISTANCE IN VARIOUS DAILY ACTIVITIES

	LEVEL OF ASSISTANCE		
ACTIVITY	NONE	SOME	COMPLETE
TOILETING	16.8%	26.2%	57.1%
EATING	27.6%	38.4%	34.0%
BATHING	10.4%	29.5%	60.0%
GROOMING	6.6%	30.4%	63.0%
DRESSING	11.4%	30.3%	58.3%
COMMUNICATING	18.7%	40.9%	40.3%
MOBILITY	42.0%	27.6%	30.4%
TRAVEL	7.5%	25.9%	66.6%
	LOW	MODERATE	HIGH
OVERALL ASSISTANCE	16.7%	28.1%	55.2%

categories. This rating, with 44% of the sample at the moderate level, reflects the general trend of the sample toward identifying a relatively level of disability.

An effort was then made to translate the level of disability into functional terms. Respondents were asked to rate their family member's need for assistance in seven activities of daily living. This information can be found in Table 10. To simplify the interpretation of the results, a three point scale was used which minimizes the fine distinctions which might be demanded on a 5 point Likert scale. Respondents were asked to indicate if the family member needed complete, some, or no assistance in toileting, eating, bathing, grooming, dressing, communicating, moving around the home, and travel in the community. With the exception of eating, communicating, and movement in the home, these variables show a consistent pattern. Approximately 60% of the sample needs complete assistance, 30% needs some help, and about 10% needs no help. These trends are reflected in the overall assistance variable which averages each respondents ratings in these areas. Translated into low, moderate, and high needs, this variable finds 16.7%, 28.1%, and 55.2% of the sample, respectively, at these levels.

Out-of-home Activity

One hypothesis that guided the design of this survey was the expectation of a relationship between the amount of formal programming and informal recreation engaged in by the person with a disability and the household's need for or use of respite. We asked the respondents to tell us how many hours per week their family members were engaged in an educational or work/vocational program and in recreation, either as part of a "program" or informally with friends. The modifier attached to these questions was that these activities take place outside of

the home. A summary of these results for the whole sample is found in Tables 11 through 13.

In the area of education (Table 11) we found that 85.33% of the sample was engaged in an average of 20.5 hours per week of out-of-home activity. 7.2% of the sample is not involved in educational activities. Initially, we were concerned by the high percentage of the sample receiving less than 10 hours a week of education. However, as we shall see, this aspect of the distribution can be attributed to young children receiving early intervention or pre-school programming.

In the sample as a whole, we found that 1360 people (47.77%) were receiving an average of 2.8 hours a week of vocational programming. If the substantial number of people (n=1045) receiving no vocational services is excluded from the computation we find the average number of hours for those actually employed or in a program is 18 hours. The large number of people receiving no vocational programming, seen in Table 12, and the high number (52.2%, n=1487) of missing data points for this item is a function of the high number of children in the sample.

In the area of recreation, 74.64% of our respondents completed the item. Their average recreational activity was 5.9 hours per week. If we concentrate on only the 57.5% of the total sample who are actually engaged in recreation this average rises to 7.66 hours per week.

Based on the pre-supposition that the type and amount of out-of-home activity would be related to the age of the person with a disability, we re-examined these data with an eye to different age ranges (Tables 14-16). In the under 5 years of age range we found that the 29.2% of our sampling in that range had an average of almost 12 hours of education activity each week (Table 14). Only 12.2% of that group was receiving no educational intervention.

For school age child 5 to 18 years (Table 15), we see that 85.32% of the sample is in school for an average of 25.48 hours a week. 97.9% of this age range gets some educational programming. In this same age range an average of 5.8 hours of out-of-home recreation was reported. If the substantial percent of individuals who are not involved in out-of-home activity are not considered, the average amount of recreation increases to 7.46 hours. In the school age group the average individual is involved in out-of-home activities for 30.23 hours a week.

Table 16 shows the portion of the sample over 18 years of age (n=282). 64.9% of the sample over 18 is involved in an average of 14.16 hours of work/vocational programming per week. If the large number of people indicating no hours of vocational activity is excluded, the average hours increase to 21.5. A substantial number (n=153, 54%) of people in this age range are engaged in some sort of educational activity for an average of 16.44 hours a week. In this same age range, 81.3% are engaged in a mean of 5.58 hours of out-of-home recreation each week. When we consider only those who actually engage in recreation, the mean is 7.11 hours. The average total amount of out-of-home activity for adults with disabilities in our sample is about 34 hours.

TABLE 11

AMOUNT OF EDUCATIONAL PROGRAMMING
RECEIVED BY ALL FAMILY MEMBERS WITH DISABILITIES

HOURS PER WEEK	PERCENT OF SAMPLE
0	7.2%
1-5	10.0%
6-10	15.8%
11-15	8.7%
16-20	6.3%
21-25	7.1%
26-30	25.0%
31-35	11.2%
36-40	7.0%
> 40	1.6%

The Mean number of hours was 20.5
The median of this distribution was 25 hours
The mode of the distribution occurred at 30 hours

TABLE 12

AMOUNT OF VOCATIONAL PROGRAMMING
RECEIVED BY FAMILY MEMBERS WITH DISABILITIES

HOURS PER WEEK	PERCENT OF SAMPLE
0	76.8%
1-5	11.6%
6-10	4.2%
11-15	1.5%
16-20	0.8%
21-25	0.6%
26-30	1.7%
31-35	0.7%
36-40	1.9%
> 40	0.3%

The mean number of hours is 28

TABLE 13

AMOUNT OF OUT-OF-HOME RECREATION ENGAGED IN BY FAMILY MEMBERS WITH DISABILITIES

HOURS PER WEEK	PERCENT OF SAMPLE
0	23.0%
0-5	42.7%
6-10	19.5%
11-15	5.8%
16-20	4.9%
21-25	1.6%
26-30	1.2%
31-40	1.0%
> 40	0.3%

The mean of this distribution was 5.9 hours.
The median of this distribution was 3 hours.
The mode of this distribution was 0 hours.

TABLE 14

AMOUNT OF EDUCATIONAL PROGRAMMING RECEIVED BY FAMILY MEMBERS WITH DISABILITIES UNDER 5 YEARS OF AGE

HOURS PER WEEK	PERCENT OF SAMPLE <5 YEARS
0	12.2%
1-5	22.7%
6-10	15.9%
11-15	22.9%
16-20	9.6%
21-25	5.3%
26-30	7.0%
> 30	4.4%
MEAN	11.98 HOURS

TABLE 15

AMOUNT OF OUT-OF-HOME ACTIVITY ENGAGED IN BY ALL FAMILY MEMBERS WITH DISABILITIES AGES 5 TO 18

HOURS PER WEEK		PERCENT OF SAMPLE AGE 5 TO 18
EDUCATIONAL PROGRAMMING		
0		2.1%
1-5		3.5%
6-10		15.8%
11-15		3.4%
16-20		4.2%
21-25		8.2%
26-30		35.0%
31-35		15.6%
36-40		9.9%
> 40		2.3%
MEAN	25.48 HOURS	
RECREATION		
0		22.3%
1-5		43.9%
6-10		18.5%
11-15		6.3%
16-20		5.1%
21-25		1.8%
> 25		2.1%
MEAN	5.80 HOURS	
TOTAL HOURS OUT-OF-HOME PER WEEK		
MEAN	30.23 HOURS	

TABLE 16

AMOUNT OF OUT-OF-HOME ACTIVITY ENGAGED IN BY FAMILY MEMBERS WITH DISABILITIES OVER 18 YEARS OF AGE

HOURS PER WEEK	PERCENT OF SAMPLE >18 YEARS
WORK/VOCATIONAL PROGRAMMING	
0	0.34
1-5	0.11
6-10	0.14
11-15	0.05
16-20	0.03
21-25	0.03
26-30	0.11
31-35	0.05
36-40	0.12
> 40	0.02
MEAN	14.16 HOURS
RECREATION	
0	0.19
1-5	0.48
6-10	0.24
11-15	0.04
16-20	0.04
> 20	0.03
MEAN	5.58 HOURS
EDUCATION	
0	0.25
1-5	0.07
6-10	0.17
11-15	0.05
16-20	0.04
20-25	0.06
26-30	0.15
> 30	0.21
MEAN	16.44 HOURS
TOTAL HOURS OUT-OF-HOME PER WEEK	
MEAN	33.99 HOURS

Respite Users/Non-users

The survey form was designed based on the premise that only a small number of people who are not currently using respite would take the time to complete the form. This assumption was a major error on our part. In fact the respondents were almost equally divided between respite users (n=1412, 49.6) and non-users (n=1391, 48.9%) (there were 1.5% (n=44) missing responses to this item). This result indicates the importance of this topic to families--especially those who are presently not using or having difficulty accessing services. There is no other obvious explanation for the high degree of participation by people who have not used respite in the last year. Since the survey was designed to gain information from respite users, a majority of the items could not be completed by non-users. If we had any inkling of the high level of participation from the non-user group we would have designed an additional section focused specifically on the issues which they confront. Unfortunately, we missed this great opportunity.

An important question we are able to address is the identification of any independent variables which seem to differentiate respite users from non-users. The relationship of all independent variables to use or non-use of respite was explored using a t test for continuous variables and the X^2 test for goodness-of-fit for all categorical variables.

The tests for group variation on the continuous variable reveal only one significant difference between respite users and non-users. The non-users of respite reported access to significantly more hours of vocational programming than users of respite (t = -2.00, df = 1346, p =<.05).

TABLE 17
CHARACTERISTIC DIFFERENTIATING RESPITE USERS FROM NON-USERS

CHARACTERISTIC	PERCENTAGE OF VALID RESPONSES				Chi Square	(df)	
	RESPITE USERS		NON-USERS				
DISABILITY:	YES	NO	YES	NO			
MEDICAL CONDITION	22.30%	28.08%	17.23%	32.39%	26.283	(1)	***
PHYSICAL DISABILITY	32.11%	18.27%	29.00%	20.62%	8.037	(1)	**
DEVELOPMENTAL DELAY	39.78%	9.17%	36.25%	13.38%	30.271	(1)	***
SPEECH IMPAIRMENT	28.33%	22.05%	23.87%	25.76%	18.271	(1)	***
VISUAL IMPAIRMENT	14.34%	36.03%	10.24%	39.39%	22.797	(1)	***
EMOTIONAL DISTURBANCE	8.53%	41.85%	6.46%	43.17%	8.123	(1)	**

IMPACT OF DISABILITY: (Type of condition)	PERCENTAGE OF VALID RESPONSES									
	RESPITE USERS				NON-USERS					
	NONE	MILD	MODERATE	SEVERE	NONE	MILD	MODERATE	SEVERE		
MENTAL	2.85%	6.58%	16.37%	24.64%	5.35%	10.31%	17.05%	16.65%	89.012	(3) ***
PHYSICAL	5.30%	9.77%	10.56%	24.75%	6.62%	12.56%	12.17%	18.29%	43.864	(3) ***
MEDICAL	8.02%	24.86%	3.11%	14.34%	9.32%	23.79%	3.36%	11.20%	14.043	(3) **
EMOTIONAL	19.79%	26.28%	NA	4.39%	22.65%	23.03%	NA	1.85%	34.411	(2) ***

LEVEL OF ASSISTANCE (Daily Activities)	PERCENTAGE OF VALID RESPONSES									
	RESPITE USERS			NON-USERS						
	LOW	MODERATE	COMPLETE	LOW	MODERATE	COMPLETE				
TOILETING	6.44%	12.51%	31.68%	10.31%	13.72%	25.35%	44.833	(2) ***		
EATING	10.83%	19.83%	19.91%	16.73%	18.35%	14.13%	61.918	(2) ***		
BATHING	3.42%	13.04%	34.10%	6.94%	16.32%	26.16%	71.433	(2) ***		
GROOMING	1.68%	13.86%	34.99%	4.85%	16.33%	28.09%	69.043	(2) ***		
DRESSING	4.03%	13.74%	32.80%	7.36%	16.58%	25.47%	58.671	(2) ***		
COMMUNICATING	7.31%	19.96%	23.36%	11.40%	20.91%	17.07%	51.439	(2) ***		
IN-HOME MOBILITY	19.11%	13.63%	17.79%	22.91%	27.48%	12.71%	32.288	(2) ***		
TRAVEL	2.03%	11.63%	36.96%	5.48%	14.28%	29.38%	72.129	(2) ***		
OVERALL	3.99%	13.22%	31.61%	10.72%	14.89%	23.57%	69.384	(2) ***		

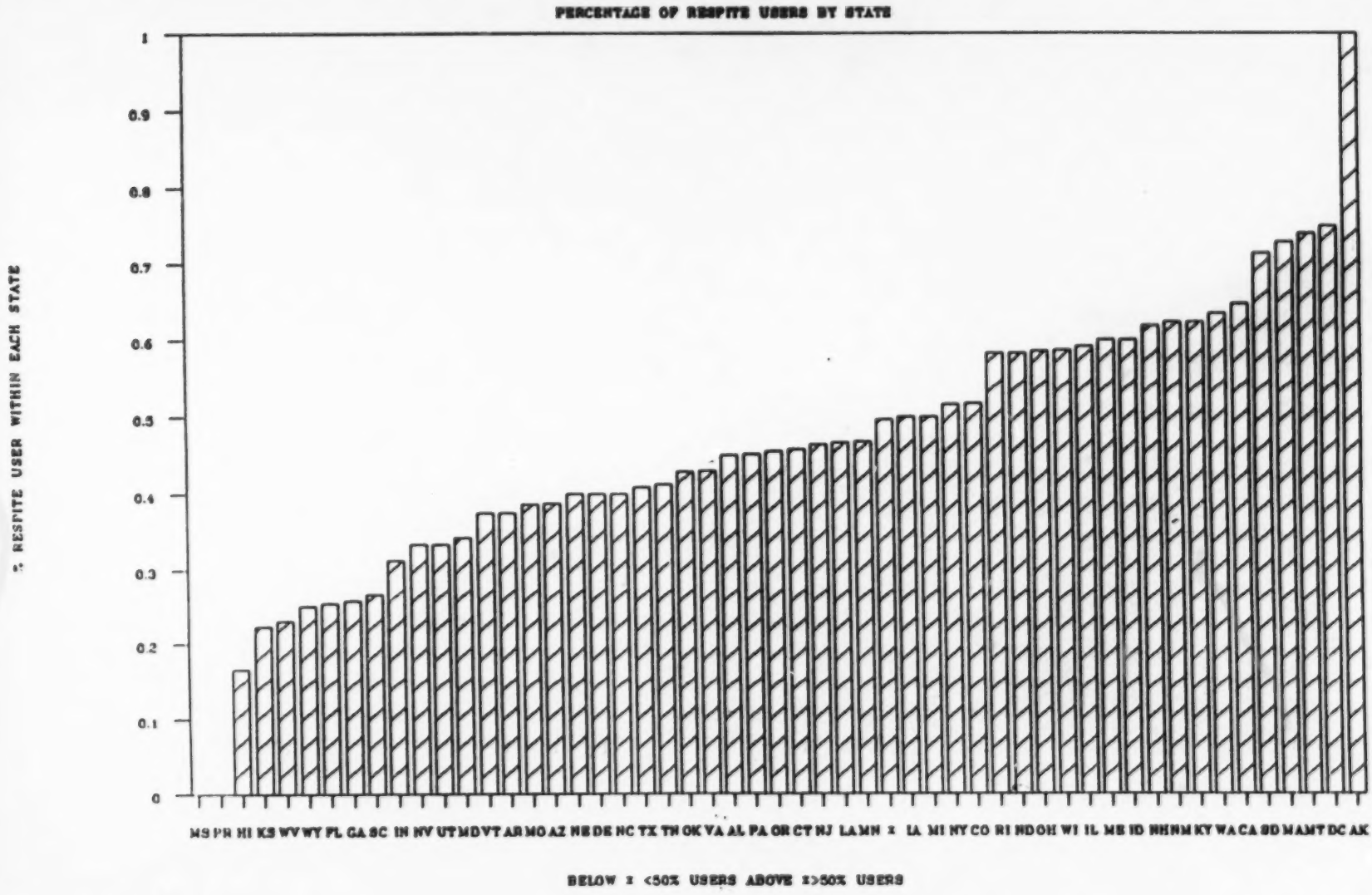
TABLE 17
CHARACTERISTIC DIFFERENTIATING RESPITE USERS FROM NON-USERS
(CONTINUED)

	PERCENTAGE OF VALID RESPONSES					
	RESPITE USERS		NON-USERS			
OPPORTUNITY COSTS (Some one in home has...)	YES	NO	YES	NO		
GIVEN UP A JOB	21.69%	28.33%	17.22%	32.76%	21.105 (1)	***
NOT TAKEN A JOB	27.96%	21.77%	24.36%	25.92%	14.854 (1)	***
REFUSED JOB CHANGE	13.32%	35.91%	11.53%	39.04%	6.286 (1)	*
CHANGED JOB HOURS	16.98%	32.50%	15.23%	35.28%	4.575 (1)	*
NOT PURSUED EDUCATION	28.34%	21.74%	24.46%	25.46%	14.137 (1)	***

	PERCENTAGE OF VALID RESPONSES										
	RESPITE USERS					NON-USERS					
EDUCATION LEVEL OF	GRADE 8	GRADE 12	COLLEGE	GRADUATE	GRAD SCH.	GRADE 8	GRADE 12	COLLEGE	GRADUATE	GRAD SCH.	
PRIME CARE GIVER	0.36%	9.13%	14.50%	13.78%	10.67%	0.57%	11.60%	14.42%	15.78%	9.27%	16.063 (5) **
OTHER ADULT IN HOME	0.48%	10.00%	11.39%	14.33%	13.77%	1.31%	11.23%	11.63%	13.17%	12.66%	13.175 (5) **

*p < .05 **p < .01 ***p < .001

FIGURE 1


PERCENTAGE OF RESPITE USERS BY STATE
% RESPITE USER WITHIN EACH STATE
1
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0
MS PR HI KS WV WY FL GA SC IN NV UT MD VT AR MO AZ NE DE NC TX TN OK VA AL PA OR CT NJ LA MN x LA MI NY CO RI ND OH WI IL ME ID NH NM KY WA CA SD MA MT DC AK
BELOW x <50% USERS ABOVE x>50% USERS

An examination of the categorical variables revealed a number of significant difference between these two group on the variable related to type and level of disability and on several of the household variables (see Table 17). On the types of disabilities identified, the X^2 test reveals that users are somewhat more likely than non-users to identify their family members as having medical conditions, physical disabilities, developmental delay, speech impairment, visual impairment, or emotional disturbance. As far as the level of disability is concerned, the pattern of responses indicates that users are more likely to describe their family member's condition as severe. Paralleling this finding is the tendency of users to indicate that the family member requires a higher level of assistance in all areas of daily living. When the opportunity cost of caring for a person with a disability was examined, we found that respite users are more likely than non-users to have given up a job, not taken a job, refused a promotion or transfer, changed their job hours, or not pursued further education. An examination of the education level within the households of users and non-users of respite reveals that non-users are more likely than users to be grammar school or high school graduates.

The other characteristic which seems to differentiate user and non-user groups is the state in which they live. Given the almost equal split between users and non-users in the sample as a whole, we would expect that if we were dealing with a system of services which had some degree of national uniformity the proportion of users to non-users within a state or other jurisdiction would roughly mirror the national percentages. As Figure 1 clearly shows there is wide state to state variation in the percentage of respite users. Both Mississippi (n =17) and Puerto Rico (n = 4) have no respite users, while Alaska (n = 13) has 100% and the District of Columbia (n = 4) has 75% users. If the distribution of states is split at

the 50% user mark, we find that 62.5% of the users are found in the 21 "user" states and 37.5% of the users are found in 31 "non-user" jurisdictions.

Experience with Respite

The centerpiece of the survey was the section which asked the respondents to describe their experiences with their local system of respite services. The non-users of respite were directed away from responding to these items. All percentages reported in this section are based on the valid responses elicited from the 1412 respondents to our survey who used respite during the last year.

As we point out in the introduction to this report the possible forms or model of respite services are seemingly endless. This perception is largely confirmed by our review of the literature. This wide variability in forms is to be applauded because it indicates an effort to be truly responsive to the needs of families by offering them what they want and not just what the provider or the local jurisdiction chooses to offer. In an effort to organize this diversity, we presented respondents with a 13 item typology of respite services as a basis for their answers. This typology, presented in Table 18, is made up of six in-home alternatives and seven out-of-home alternatives. No functional definitions were given of these types other than the identifiers as found in Table 18. The sole exception to this was an effort to elicit information on the use of generic day care by specifying "community day care provider" on the survey form.

TABLE 18

AVAILABILITY, UTILIZATION, & DESIRABILITY
OF VARIOUS RESPITE MODELS AS REPORTED BY RESPITE USERS

MODEL	AVAILABILITY REPORTED BY % OF USERS	UTILIZATION REPORTED BY % OF USERS IF AVAILABLE	DESIRABILITY RATING *IF NOT* AVAILABLE
IN-HOME:			
FAMILY, FRIEND, NEIGHBOR	62.25%	76.68%	1
TRAINED RESPITE PROVIDER	44.69%	52.61%	2
LICENSED PRACTICAL NURSE	16.71%	32.63%	8
FORMAL RESPITE AGENCY	42.14%	45.71%	7
OTHER PERSON	17.99%	68.50%	10
OTHER APPROACHES	5.38%	71.05%	NA
OUT-OF-HOME			
FAMILY, FRIEND, NEIGHBOR	42.14%	61.85%	3
PRIVATE HOME	26.42%	40.48%	6
RESPITE CENTER	22.80%	36.65%	4
GROUP HOME	5.17%	5.48%	9
INSTITUTION	6.94%	12.24%	12
DAY CARE PROVIDER	13.46%	32.11%	5
OTHER	1.42%	80.00%	11

Availability of Respite

Respondents were asked to identify the models of respite that are available in their community. The responses to this question are found in the first column of Table 18. For both in-home and out-of-home respite the most available form is the largely informal network of family members, friends, and neighbors. In the in-home category, a trained provider and a respite agency are listed as most available forms of respite after the informal network. We interpret the "Other Person" that is available in 17.99% of the cases to be essentially a sitter with no specialized training. The fact that a Licensed Practical Nurse (LPN) is identified in only 16.71% of the responses may indicate a lack of need and knowledge rather than availability. It is unlikely that most people would think of this highly professionalized approach as viable unless they needed it because of a family member's medical condition. Idiosyncratic approaches to in-home-respite were reported 5.38% of the time.

For out-of-home respite care, private homes (again the untrained "sitter") and respite centers are indicated as the next most available forms after the informal network. Community day care is perceived as available in 13.46% of the cases. We were surprised to find that group homes and institutions were only available 5.17% and 6.94% of the time respectively. A small number (1.42%) of the respondents reported unique approaches to out-of-home respite.

Utilization of Respite

The second column in Table 18 reports the percentage of time a particular approach to respite is reported as used **when it is identified as available**. It

should not be surprising that the approaches that are dependent on individual arrangements are the one most frequently used when they are available. Interestingly, trained respite providers and agencies are only used about 50% of the time. LPNs, respite centers, and day care providers are all used about the same amount of the time. The least used options are institutions and group homes. It rather surprising that the institutional option is used about twice as often as group homes.

The figures on Table 19 take this rate of utilization one step further and present the average number of hours that each respite option was used in one month. The second column of this table indicates the number of respondents who used that option. Although used by a relatively small portion of the sample, the Licensed Practical Nurse has the largest average monthly hours of usage. 90% of all respite users average 28.27 hours of in-home-respite per month. This figure seems to indicate that where it is available, families are making good use of respite.

The high average hours of use associated with private homes, respite centers, group homes, and institutions suggest that these out-of-home options are usually used for overnight stays. The few hours of monthly use of community day care is interesting. This seems to indicate that very few parents of children with disabilities are able to use day care in order to work on a regular basis. The average monthly use of out-of-home respite is 22.3. This represents the usage of 34.9% of all respite users. The figure of 43.7 hours a month of average use for all forms of respite indicates that these families are making use of both in-home and out-of-home options in the same month.

TABLE 19

AVERAGE HOURS OF VARIOUS MODELS OF RESPITE
USED IN ONE MONTH AS REPORTED BY RESPITE USERS

MODEL	AVERAGE NUMBER OF HOURS USED	PERCENT OF RESPITE USERS
IN-HOME:		
FAMILY, FRIEND, NEIGHBOR	14.75	55.682%
TRAINED RESPITE PROVIDER	18.77	27.516%
LICENSED PRACTICAL NURSE	37.28	6.412%
FORMAL RESPITE AGENCY	17.65	22.565%
OTHER PERSON	30.91	14.610%
OTHER APPROACHES	25.07	4.789%
AVERAGE IN-HOME USAGE	28.27	90.097%
OUT-OF-HOME		
FAMILY, FRIEND, NEIGHBOR	12.90	30.357%
PRIVATE HOME	26.45	12.825%
RESPITE CENTER	31.48	9.821%
GROUP HOME	45.01	0.325%
INSTITUTION	44.75	1.299%
DAY CARE PROVIDER	2.48	12.744%
OTHER	5.85	4.383%
AVERAGE OUT-OF HOME USAGE	22.30	34.903%
AVERAGE USE OF ALL TYPE OF RESPITE	33.25	100.000% (n = 1232)

308 respondents used both in-home and out-of-home respite.
Their average usage was 43.70 hours.

The data indicate that 479 user households (37%) used only one type of respite option. A nearly equal number (n=472) used 2 types of respite. 23% of respite users employ 4 or 5 alternatives. Three respondents report using 6 or 7 different models of respite within one month. The average household used two types of respite. In some cases, this reflects a use of several forms of the same type of respite, rather than the use of one in-home and one out-of-home model. In fact, 38% of users report multiple forms of in-home respite, while 27% used several out-of-home options.

Relating the descriptive variables discussed earlier to the amount of respite used revealed only one statistically significant correlation. There is a weak positive correlation between the overall level of disability and the total hours of respite reported ($r = .1749, p < .001$). On average, there is some small increase in respite usage as the level of disability becomes more severe.

Of respite users, 83% indicated that some part of the respite they used was at least partially subsidized by some source of public funds. When we asked how this publicly supported respite was allocated, 595 of this group indicated that the had an average allocation of about three days of respite per month (24.82 hours). 24.82% of the group said that they did not know what the allowable allocation was and 16.17% reported that respite was allocated on an "as needed" basis. In response to questions about the need for additional respite, 40.93% of respite users said they needed an average of 18.3 more hours of in-home respite each month. 16.61% of the users felt they could use 20.4 more hours of out-of-home respite each month.

Preferred Models of Respite

The final column of Table 18 shows the desirability rating of certain forms of respite among respite users in areas where that approach is currently **not available.** The rating score reflects the ranking of these approaches based on the number of times each was selected as desirable. These rankings seem to demonstrate a clear preference for less formal and individual relationships with providers (family, friends, and neighbors and individual trained providers). Respite centers and day care providers are ranked closely together as the next most preferred options followed by private homes. Formal agencies and LPNs seem to fall together as a grouping of professionalized approaches which are not quite as desirable as the more informal approaches. These are followed by group homes. The somewhat ill-defined options of "other person" in-home and "other" out-of-home are found next in the ranking. The sample sees respite services in an institutional setting as the least desirable option. This mirrors the relatively low rate of utilization observed for this option.

Experience with Providers

The next group of variables we examined looked at parents' experience with respite providers. Table 20 provides an overview of some of the issues in their relationship with respite agencies. We see that there is wide variability in the amount of control that parents have over selecting the person who will be their actual provider. In all but approximately 23% of the cases there is some care giver input into the selection of the respite person. The second part of the table reveals that most care givers feel that the individuals providing respite services are

TABLE 20

EXPERIENCE WITH RESPITE AGENCIES

	% OF RESPITE USERS
PROVIDER SELECTED...	
BY CARE GIVER	30.40%
FROM APPROVED LIST	16.80%
IN CONCERT WITH AGENCY	29.90%
BY AGENCY	22.90%
QUALIFICATION OF PROVIDERS	
UNQUALIFIED	3.20%
POORLY QUALIFIED	6.80%
MINIMALLY QUALIFIED	18.10%
WELL QUALIFIED	54.30%
VERY HIGHLY QUALIFIED	17.60%
PROVIDER WILL CARE FOR OTHER CHILDREN	57.00%
AT AN ADDITIONAL CHARGE	52.00%
AVERAGE ADDITIONAL CHARGE	$2.82 per hour

relatively well qualified. About 72% of the respondents feel that providers are well or very highly qualified.

One major contribution of the advisory panel to the questionnaire was the inclusion of a question which explored the degree of flexibility of providers around being sitters for siblings without disabilities in addition to providing respite for the member of the family with a disability. 57% of the responding respite users indicated that their providers were willing to watch other children. In most cases (52.74% of users) there was an additional charge for this services which averaged $2.82 per hour.

Cost

From a public policy perspective two important questions are: 1) how much do these services cost the public sector; and 2) how much does this thing called respite cost families over and above the typical costs of baby-sitting and child care? This study did not take a detailed look at this issue but, from the perspective of the family, we did collect some relevant information. Respondents were asked about the reimbursement rate for publicly subsidized respite. The vast majority of respondents left this item blank or checked a box that indicated that they did not know. The 719 replies we did receive indicated an average rate of $5.85 an hour. There were many different answers ranging from three respondents who indicated there was no public rate to single individuals who cited rates of $32.00, $35.00, $40.00, $50.00, and $90.00 an hour.

To the question which asked how much money had been spent out of pocket for publicly subsidized respite during the last month, 998 individuals responded

610 of these households encountered no expenditure. On the other extreme were 23 households which spent in excess of $200.00 including two whose monthly bill for respite was more than $1000.00. The average monthly cost for households that had some additional expense was $57.14. A final fiscal question asked the respondents for the hourly rate they pay for respite which they pay for completely on their own. The average hourly rate reported by 767 respondent was $4.36.

Scheduling

In conversations with parents, project staff have been told that respite agency requirements for advance scheduling were a major problem. Three questions in the survey addressed this issue. The responses to these items are found in Table 21. The image of respite care that emerges is not of one that is particularly flexible or responsive to the shifting demands of everyday life. 71% of users report that they must schedule respite at least four days in advance. In 18.8% of the cases this lead time is more than two weeks. 53.8% of users indicate that the existing scheduling requirements usually meets their needs. However, this means that 46.3% of the respondents work with a system which does not respond to their needs.

Perhaps the real test is whether the system of respite is able to respond, not so much to the day-to-day shifts of schedule, but to major crises. 46.7% of respite users report that the system that they use cannot usually meet their needs in a time of emergency. Only 27% of the sample report sufficient flexibility to respond to a crisis. An almost equal number (26.6%) indicate that they have never encountered a crisis in which they needed emergency respite support.

TABLE 21

FLEXIBILITY IN SCHEDULING RESPITE AS REPORTED BY RESPITE USERS

	% OF USERS
HOW FAR IN ADVANCE MUST RESPITE BE SCHEDULED?	
SAME DAY AS NEEDED	5.90%
ONE TO THREE DAYS IN ADVANCE	23.20%
FOUR DAYS IN ADVANCE	25.60%
ONE TO TWO WEEKS IN ADVANCE	26.60%
OVER TWO WEEKS IN ADVANCE	18.80%
DOES THIS SCHEDULING ARRANGEMENT MEET YOUR NEEDS?	
NOT AT ALL	10.80%
SOME OF THE TIME	35.40%
ON AVERAGE, YES	27.30%
MOST OF THE TIME	20.90%
ALWAYS	5.60%
IN AN EMERGENCY CAN YOU GET THE RESPITE YOU NEED?	
NEVER	17.60%
ONLY SOMETIMES	29.10%
ON AVERAGE, YES	12.40%
MOST OF THE TIME	11.20%
ALWAYS	3.20%
NO NEED FOR EMERGENCY RESPITE	26.60%

TABLE 22

PROBLEMS ENCOUNTERED BY FAMILIES USING RESPITE SERVICES

PROBLEM	PERCENT OF USERS REPORTING THIS PROBLEM
TOO LITTLE TIME ALLOCATED	40.8%
RELUCTANT TO USE STRANGERS	39.5%
TOO LITTLE TIME TO MAKE ARRANGEMENTS	27.0%
POOR QUALITY OF AVAILABLE SERVICES	25.4%
OTHER REASONS	22.7%
LACK OF REFERRAL INFORMATION	20.5%
AVAILABLE SERVICE TOO EXPENSIVE	18.8%
DISABILITY DID NOT FIT ELIGIBILITY CRITERIA	18.3%
EXTENSIVE WAITING LISTS	18.3%
ADDITIONAL COST FOR OTHER CHILDREN	17.8%
LACK OF PUBLICLY SUPPORTED RESPITE	14.9%
AVAILABLE SERVICE INAPPROPRIATE	14.2%
FAMILY DID NOT QUALIFY FOR SUPPORT	12.0%
LACK OF TRANSPORTATION	6.8%
PROBLEM WITH THE PERSON WITH A DISABILITY	6.3%

Problems

In another series of items, respite users were asked to identify which of 15 possible problems with respite they had encountered. Table 22 presents these problems rank ordered according to the frequency with which they were selected. No single problem was encountered by a majority of the users. However, about 40% of them indicated that limited allocation of respite time and the need to leave their family members with a disability with a stranger were problems for them. The scheduling issue discussed in the previous section was cited by 26.98% of the users. A quarter of the respite users had encountered problems with the quality of services that were available and almost 23% had unique problems which fell outside the categories provided on the questionnaire. Given that respondents to this item were already respite users, it is not surprising that some problems were cited infrequently. Issues such as source of referral, cost, waiting list, eligibility criteria, lack of public supported services, failure to qualify for services, and lack of transportation could be expected to rate much higher with non-users.

Satisfaction

A series of items endeavor to gain a sense of the respondents satisfaction with the system of respite services, their perception of the value of respite, and their sense of the degree to which the system of service will improve over the next few years. As the items summarized on Table 23 show, respite users are, in general, fairly satisfied with the respite options which they use. 59.3% of users indicate that they more satisfied than not, while 20.6% of fall at the other end of the satisfaction distribution. This high level of satisfaction is paralleled by the impact that families attribute to respite services. 74% of the families reported that this

service has made a significant difference in their ability to care for person with a disability at home. On the other extreme, 17.2% of the respondents were neutral in their evaluation of the value of respite and 8.9% tended to minimize its affect. 34.6% of the respite users indicated that without respite services they would have considered out-of-home placement for their family member.

When we explored whether the respondents feel that they have adequate input into planning services and sufficient control over the services, only 37.3% and 32.6% of respite users, respectively, expressed satisfaction with this aspect of the service system. This low level of satisfaction with the system is echoed in the range of responses to a question which asked for an evaluation the potential for positive growth in the community's system of family supports. Only 3.9% of the sample indicated a high expectation for change. 12.9% of the respondents were optimistic, while 45.3% had limited expectations. 37.9% of the sample had essentially no expectation of change for the better.

Why Respite?

A final group of survey items asked users to identify the reasons they used respite. Table 24 displays the results of this section. The frequencies reflect the percentage of users who identified a particular reason for using respite. As we review the results, it is very difficult to separate the first two reasons listed -- clearly time for socializing can be a major way to alleviate stress. The next two items in the listing make an interesting pair in their complementary concern for a member of the family other than the care giver. Specifically the use of respite as a method for expanding the social experience of the person with a disability is intriguing. Respite can and is used to fulfill the role that social networks and

TABLE 23

SATISFACTION WITH AND SENSE OF CONTROL OVER RESPITE AND OTHER SERVICES AS REPORTED BY RESPITE USERS

	% OF USERS
HOW SATISFIED ARE YOU WITH THE RESPITE YOU USE?	
NEVER	2.70%
SOMETIMES SATISFIED	17.90%
ON AVERAGE, SATISFIED	20.10%
MOST OF THE TIME SATISFIED	36.50%
ALWAYS SATISFIED	22.70%
THE OPINIONS OF PARENTS ARE ADEQUATELY CONSIDERED IN PLANNING RESPITE AND OTHER SERVICES	37.30%
PARENTS HAVE ADEQUATE CONTROL OVER RESPITE AND OTHER SERVICES	32.60%

community involvement provide for children without disabilities. The relatively low rating of respite as child care for parental employment leads us to wonder if that might not be a function of the relatively prosperous nature of our sample. In a less affluent group, we would expect to see a greater need for respite for longer periods of time during the workday.

Needs for Services and Information

Both respite users and non users were asked to complete the balance of the items on the survey. These items dealt with the content and format of materials which may be developed as a result of this project and entailed prioritizing respite within the framework of other forms of family support.

Table 25 ranks 13 types of information in the order of their rating by all respondents. Over 90% of the respondents rated each of these options on a 5 point Likert scale (1 least preferred to 5 most preferred). The scores in the rating column reflect the average scores associated with these items. While the spread on all of the items is only one point, it is interesting to note that items seem to fall into related clusters. The first three reflect a functional perspective on the knowledge necessary to organize, manage, or at least fully understand respite services. The next three items are concerned with the skills and knowledge needed to achieve systemic change. The next pair of items focused on working with and evaluating direct service. This is followed by information on two types of best practices. The next pair both deal with grassroots organizing. The least desired information is documentation on the value of respite. This is not surprising since all of the respondents to this survey have clearly demonstrated

TABLE 24

REASONS FOR USING RESPITE REPORTED BY RESPITE USERS

REASONS FOR RESPITE	REPORTED BY % OF USERS
TIME FOR ENTERTAINING/SOCIALIZING	75.92%
RELIEF FROM EMOTIONAL STRESS	73.51%
TIME & ATTENTION TO OTHER FAMILY MEMBERS	59.21%
SO FAMILY MEMBER CAN HAVE CONTACT WITH OTH	42.85%
VACATIONS	42.21%
TIME FOR HOUSEHOLD ROUTINES	41.29%
EMERGENCIES	39.59%
TIME FOR EMPLOYMENT	29.46%
ILLNESS IN THE FAMILY	27.97%
ASSISTANCE BEFORE OR AFTER SCHOOL	23.65%
OTHER	12.18%

TABLE 25

INFORMATION DESIRED BY FAMILIES TO ASSIST THEM IN IMPROVING SERVICES IN THEIR COMMUNITIES

TYPE OF INFORMATION	AVERAGE RATING
SOURCES OF FUNDING FOR SERVICES	4.563
HOW TO RECRUIT, TRAIN & SUPERVISE PROVIDERS	4.452
VARIOUS RESPITE ALTERNATIVES	4.251
UNDERSTANDING OF THE SERVICE STRUCTURE	4.136
HOW TO ADVOCATE AND LOBBY FOR CHANGE	4.106
KNOWLEDGEABLE POPLE TO CONTACT	4.065
HOW TO EVALUATE SERVICES	4.030
HOW TO WORK WITH PROVIDERS	3.999
DESCRIPTION OF MODEL PROGRAMS	3.998
AVAILABLE FAMILY SUPPORT OPTIONS	3.950
HOW TO ORGANIZE	3.873
CONTACT WITH OTHER FAMILIES	3.660
DOCUMENTATION OF RESPITE'S VALUE	3.639

the high value which they place on respite. They do not need further research to confirm their own knowledge.

Any effort to communicate with people needs to be sensitive to what they see as the most accessible way for them to process the information. Using a three point scale, respondents were asked to indicate preference regarding the format of respite materials (see Table 26). It seems that a single book is the most appealing approach for the prosperous educated individuals in this sample. Respondents indicate a willingness to spend an average of $17.00 for such a book. The next highest ranked choice, a newsletter on respite and related family support issue, was selected by more respondents but at a somewhat lower ranking than a book. Respondents would pay $10.50 for a subscription to such a newsletter. The most frequently selected option was a regular column in *Exceptional Parent* but , on average, it was ranked lower than three other choices. The training package option was described as including a videotape, hand-outs, and workshop agendas that are used by an agency or advocacy group to train parents. This option along with the option of a videotape alone, periodic articles in *Exceptional Parent*, and a series of pamphlets were the least frequently selected options and received the least desirable ratings.

Support Needs

To put this project with it emphasis on respite in context, the final series of items on the survey asked respondents to rate nine forms of family support services, including in-home and out-of-home respite, according to their level of need for that support. Again the ranking was on a five point Likert scale with a higher score indicating a greater degree of need. Each item was ranked based on

TABLE 26

PERFERRED FORMATS FOR PRESENTING INFORMATION CONCERNING RESPITE

FORMAT	AVERAGE RATING	FREQUENCY OF SELECTION
SINGLE VOLUME	2.292	1330
NEWSLETTER	2.098	1552
HOT LINE	2.048	1335
MAGAZINE COLUMN	2.038	1579
SERIES OF PAMPHLETS	2.025	958
TRAINING PACKAGE	1.990	1093
PERIODIC ARTICLE	1.869	855
VIDEOTAPE	1.817	398

TABLE 27

TYPES OF SUPPORT SERVICES DESIRED BY FAMILIES

TYPE OF SUPPORT	AVERAGE RATING
FUTURE PLANNING	4.293
SPECIALIZED SERVICES	3.772
TEMPORARY IN HOME RESPITE	3.559
SUPPORT FOR THE WHOLE FAMILY	3.356
ADEQUATE HEALTH COVERAGE (INSURA	3.335
FINANCIAL ASSISTANCE	3.331
INFORMATION AND REFERRAL	3.090
DAY PROGRAMMING	3.012
TEMPORARY OUT OF HOME RESPITE	2.954

its average rating by all respondents. Table 27 presents the results of this ranking.

It is important to point out that although "respite" was the focus of this survey and respondents are very interested in this topic respite is not their most pressing need. In fact out-of-home respite (as opposed to in-home respite) received the lowest need rating of any item. The highest rating was given to a need for assistance in future planning to assure the long term well-being of the family member with a disability. This was followed by a need for specialized services which addressed the disability related needs of the person. In-home respite was ranked as the third highest priority item. Supports which address the needs of the entire family (sibling counseling, etc.), adequate health insurance coverage, and financial assistance to meet some of the costs associated with their specialized needs are found clustered together in the center of the ranking. A need for information and referral to services and a need for day programming round out the ranking.

Differences Between Respite Users and Non-users

As was the case with some of the independent variables reported earlier there are some significant differences between the way users and non-users of respite prioritize their needs for information and services. These difference are clustered in Table 28. It should be pointed out here that the magnitude of these differences is relatively small, a matter of a few percentage points per cell in a X^2. Yet, the size of our sample allow us to affirm these differences with a high level of probability.

TABLE 28

DIFFERENT NEEDS FOR SERVICES AND INFORMATION AS IDENTIFIED BY USERS AND NON-USERS OF RESPITE

NEED	PERCENTAGE OF VALID RESPONSES											
	RESPITE USERS					NON-USERS						
INFORMATION CONCERNING: PRIORITY LEVEL:	1(LOW)	2	3	4	5(HIGH)	1(LOW)	2	3	4	5(HIGH)	Chi Square	(df)
MODEL PROGRAMS	2.03%	3.62%	11.50%	12.66%	21.06%	2.17%	2.61%	9.12%	10.41%	24.80%	23.176	(4) ***
EVALUATION	1.38%	3.34%	12.34%	15.17%	18.16%	0.83%	2.59%	8.57%	13.40%	24.21%	47.845	(4) ***
WORKING WITH PROVIDERS	1.37%	3.61%	12.54%	13.60%	17.33%	1.18%	2.12%	9.25%	13.68%	23.32%	48.55	(4) ***
AVAILABILITY OF SERVICES	3.53%	4.37%	10.09%	11.68%	20.99%	2.99%	3.30%	7.60%	9.13%	26.42%	36.962	(4) ***
	RESPITE USERS					NON-USERS						
TYPES OF SERVICES PRIORITY LEVEL:	1(LOW)	2	3	4	5(HIGH)	1(LOW)	2	3	4	5(HIGH)		
IN-HOME RESPITE	4.38%	4.90%	9.96%	10.03%	20.94%	9.47%	5.96%	8.56%	8.68%	17.13%	67.931	(4) ***
OUT-OF-HOME RESPITE	10.46%	6.99%	9.38%	8.28%	14.92%	16.35%	7.52%	8.73%	6.83%	9.95%	61.931	(4) ***
FINANCIAL AID	7.63%	6.12%	9.49%	8.13%	19.05%	10.96%	6.73%	10.17%	6.65%	15.04%	33.155	(4) ***
FAMILY SUPPORT	7.43%	6.07%	9.39%	9.96%	17.62%	9.02%	7.36%	10.03%	9.39%	13.75%	20.836	(4) ***
SPECIALIZED SERVICES	5.44%	4.02%	7.35%	9.19%	24.47%	6.60%	4.35%	8.26%	9.23%	21.09%	11.182	(4) *
	RESPITE USERS					NON-USERS						
LEVEL OF EXPECTATION:		LOW	SLIGHT	MODERATE	HIGH		LOW	SLIGHT	MODERATE	HIGH		
OPTIMISM CONCERNING CHANGE		18.45%	22.51%	7.73%	2.44%		19.62%	22.69%	5.06%	1.50%	20.362	(3) ***

*p < .05 ***p < .001

The pattern of responses to the need for information reveals that non-users are somewhat more likely to place a higher priority on information regarding model programs, evaluation, how to work with providers, and the current availability of services. The pattern of ranking is reversed when it comes to identifying service needs. Respite users tend to rank the need for in-home respite, out-of-home respite, financial aid, supports for the whole family, and specialized services as a higher priority than non-users. Finally, respite users are just slightly more optimistic than non-users about the possibility of the service system changing in ways that meet their needs

Conclusions

The motivation behind this study was to explore the potential market for materials which would enable parents to become better informed consumers of respite services. In this study we have developed a very clear picture of the experience and needs of middle and upper-middle class families as they relate to respite services. Additionally, this sample is most representative of families with relatively young children with primarily developmental and physical disabilities. There is little indication in the data that we have explored the special needs and problems which confront lower income and minority families or the parents of older children, adults living at home, children with emotional disturbance, or children with complex medical problem such as being respirator dependent. So before proceeding to synthesize our findings, we would like to outline some specific methods we would use in the development of materials to overcome this limitation.

Addressing the Needs of Under Represented Families

It was not our intent to conduct a study which would touch all bases in the development of parent-centered materials on respite and other services, but rather to establish something of a baseline from which to work. We approached this undertaking with an understanding that the primary target audience for parent material would be the kind of population that is represented in the *Exceptional Parent* sample. In this regard, this project has been most successful in achieving it primary objectives. We have our baseline. We have identified a need. We have strong indications regarding content and form.

However, as we design a plan to actually develop materials to address the needs identified here, we must also insure that the materials do not exclude the needs of families with lower incomes and less education. Further, such resources on an important issue like respite must be useful to parents of children with emotional disturbance, children with serious illness, and children with specialized medical problems.

The focus of our materials will be to help all parents move from being a client of a social service system to becoming an informed consumer. Attaining this goal will be a different process for a single parent of a technology dependent premature infant who lives in an inner city than for a two income suburban family of a child with emotional disturbance or a rural farm family of a 35 year-old man with severe mental retardation. However, based on our experience in dealing with a range of families, we feel that there is a common core of information needed to address the problems all parents encounter when placed in a client role. This common core of information will probably make up 75% of any future materials. The other 25% needs to target the unique needs of specific groups of parents or special issues as they relate to a particular disabling condition.

In order to address the broadest possible audience, it may necessary to develop a range of complementary materials. At this point, based on what we have learned from the *Exceptional Parent* sample, we could begin work on some materials tommorow. However, projections of the variations in form and content that would address the special needs of other groups of parents is, at this time, pure hypothesis. If funded to actually develop parent/consumer material, the first activities would be aimed at addressing these lacunae in our knowledge.

Three strategies will be utilized to gain access to groups not adequately represented by the results of the present study.

1) Contacts have already been made with several national organizations who would agree to directly distribute copies of the Respite Survey Questionnaire to a portion of their mailing list. These organization are represent groups not found in the *Exceptional Parent* sample. For example Sick Kids (need) Involved People (a national organization of parents of technology dependent and seriously ill children), Alliance for the Mentally Ill (an organization of parents and relatives of people with mental illness), and the two NIDRR Research and Training Centers on Emotional Disturbance in Florida and Oregon would all be willing to participate. The basic survey would be supplemented with a few items which would target any special problems encountered by these respondent groups.

2) Phone interviews with a random sample of the non-users who responded to the respite survey and indicated a willingness to be interviewed will be conducted. These interviews will explore the reasons why they do not use respite. This interview data will inform efforts to identify barriers to respite services and strategies for overcoming them.

3) Focus groups will of necessity be a major strategy used during the development of material to test audience reaction to the form and content. However, the first use of this strategy would be to explore the unique needs and concerns of low income and minority group parents. A series of these groups would be held around the country arranged in conjunction with indigenous community organizations. These forum would explore the topics covered in the respite survey but would focus primarily on the special problems confronting these families. Current contacts which HSG has with urban family support groups in New York and Chicago would provide a base for the first of these forums.

Findings

This study clearly demonstrates that respite is a valuable resource for families who are able to utilize it. The families are essentially pleased with the individuals who provide them with respite. However, they seem to have some substantial problems working out the details of obtaining this support. Lack of flexibility, arbitrary limits on use of the service, the inability of the "service system" to

consistently respond to crises, all point to services which have not yet taken the concept of parental empowerment to heart. This experience is mirrored in the families' evaluation of the degree to which they are active partners in the planning and implementation of the programs which affect their families.

There is a clear preference among families for respite arrangements which are congruent with the normative community approaches to providing for child care or sitters. The parents want to be in control and have the provider responsible to them. They prefer someone they know or, failing that, someone who is clearly seen as being their employee. As soon as the respite alternatives begin to move out of the local community or begin to minimize parental control parents become less prone to endorse them.

Some of the findings of this study point to a substantial social cost as parents--usually women--with a wide range of education and talents are unable to pursue educational and career goals because of the extraordinary demands of raising a child with a disability. The issue of day care in general has come to the front of the national policy agenda because of the economic impact that the lack of resources in this area has had. What has not been addressed is the failure of respite or "generic" day care to provide for the needs of parents of children with disabilities on a day to day basis. Yet, the economic impact on these families is certainly more profound than the case of the parent who misses work periodically because day care arrangements fell through. The image of respite that seems to emerge is something which the public sector regards as an extraordinary resource made available to families. However, families clearly regard it as a necessary and regular part of daily life. Some of what we see here points in the direction of

expanding respite so it that loses some of it specialness and is integrated into a comprehensive system of day care.

The failure to develop a coherent vision of the needs of parents and their children with disabilities is most evident in the wide variation in state-to-state use of respite. This indicates some major differences in the availability and accessibility of services.

As we look at what parents say they want in the way of information, it seems to fall into two major areas. First they want to be able to exercise control over the services which affect their home life. Second, they want a substantive role in forming or reforming the system of services in a manner which is really responsive to their needs.

When we asked what their major needs are, parents' first two primary concerns are for the overall welfare of their child. Only after their pervasive concern for the future of their child is addressed does respite, or "relief" for them, become a priority. Perhaps as a comprehensive system of community-based supports including respite become the rule rather than the exception parents will be able to look to the future of their child with a little more security.

Implications for Developing Training Materials

In a series of interviews conducted at the same time as this survey (Agosta & Knoll, 1988), we asked families about family support in general. The first thing many parents and other care givers mention is respite. For some of the families interviewed "family support" is "respite." It has not occurred to these care givers

that family support could entail anything beyond the temporary care of a family member with a disability by someone outside of the family. In many cases, this narrow definition of the term can be attributed to a limited awareness of the more expansive approach to family support that is beginning to take root around the country. For while a few forward looking states and a number of advocates are promoting the idea of family support as "anything it takes" to maintain the integrity of the family (Center on Human Policy, 1986; Taylor, Racino, Knoll & Lutifiyya 1987), the reality is that in most states family support is more narrowly defined. Often family support is only respite. And as we have seen, even this limited contribution to family welfare is not universally or equitably distributed throughout the country.

Our preliminary review of the literature suggested that although there was a growing body of work on respite, it was for the most part technical and geared to the needs of providers. This sense has largely been confirmed by our indepth review of the literature. There is little clear evidence that the voice of parents has been heard in the design of services or in the literature which contributes to the formation of these services. At best what can be said is that there are materials available if parents wish to become service providers and establish their own respite agency.

When it comes to family **supports** there seems to be some inherent contradiction in calling on parents to assume the added role of becoming a service provider. The underlying value behind most of the activity in this area is the belief that parents should be supported so they can devote their major energies to parenting a child with a disability or serious illness. In fulfilling this role they

make a major contribution to the life of the community. They should not be called on to further dissipate their energies by developing services. Rather, the community has some responsibility to support its families and the child rearing efforts of all its parents. The demands of raising a child with a disability or serious illness are substantial enough in and of themselves.

Traditionally, the demands of care giving have been used as a rationale for seeing parents of children with disabilities as a fairly powerless group who often found themselves at the mercy of professional service providers and public administrators. So often these professionals assumed the role of telling the parents not only what they need, but what they can have (Dybwad, 1984). The service that has become known as respite is an effort to support families. These programs are at least nominally community-based and family-centered services in line with the ideals expressed much of current "family" literature. Yet we found little evidence that the respite system has truly left behind the traditional professional-client relationship. There is no clear evidence that the majority of respite programs are consistent with the values of consumer empowerment and control. If there were consistency, we would expect to find substantive consumer involvement in the design, management, and evaluation of support services. We did not.

There is a growing awareness that the way services are provided can have a major impact on overcoming this perception of powerlessness (Dunst, Trivette, & Deal, 1988) In other words, people become powerful by having experiences that affirm their abilities; people are made powerless through experiences which demean their competencies. This leads directly to service models based on a equal

partnerships between parents and professionals which assume two basic premises: 1) all families and persons with disabilities are potentially willing and capable to make responsible decisions; and 2) families know best what will make their life easier, more productive, and secure for their child. Any material developed based on this project must start from this perspective and be structured around experiences which will affirm for parents their ability to manage respite for their own family member. Moreover, really valuable material will foster the development of skills of critical analysis and organization which parents will be able to utilize in all arenas of life.

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APPENDIX 2:
RESPITE SURVEY QUESTIONNAIRE

Exceptional Parent Magazine
P. O. Box 657
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SECOND CLASS
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MAILING OFFICES

SUPPLEMENT TO THE OCTOBER 1988 EXCEPTIONAL PARENT MAGAZINE

RESPITE CARE SURVEY

Dear Parent or Guardian:

Respite care is an important service for families who have a member with a disability. Respite care is any service or program which provides care for a person with a disability while the primary care-giver is engaged in some other activity.

We all need to know about the respite services available in communities across the country. We hope to design materials that will:

1) enable parents to become informed critical consumers of respite services, and
2) provide parents with a guide for advocating systems change on behalf of all families.

Complete and mail this form to us as soon as possible. Be sure to use the attached pre-addressed and pre-paid envelope.

Thank you,

Human Services Group/*Exceptional Parent* Magazine

RESPITE CARE SURVEY

Unless otherwise directed, please check only one option per question.

1. What is your relationship to the member of your family with a disability?
   ____ (1) Mother
   ____ (2) Father
   ____ (3) Other (specify): _____

ABOUT YOUR CHILD OR ADULT WITH A DISABILITY

2. How old is your child or adult with disabilities?
   _____Year(s) _____Month(s)

3. Indicate nature or type of disabling condition (check all that apply).
   ____ (1) Medical condition
   ____ (2) Physical disability
   ____ (3) Developmental delay or reduced capacity to learn daily living skills
   ____ (4) Speech impairment
   ____ (5) Hearing impairment or deafness
   ____ (6) Visual impairment or blindness
   ____ (7) Emotional disturbance or behavior problem
   ____ (8) Other:_____

4. To what extent has your family member's disability affected his/her MENTAL or INTELLECTUAL DEVELOPMENT (the capacity to learn new things and apply learned skills as needed)?
   ____ (1) Not at all ____ (3) Moderately
   ____ (2) Mildly ____ (4) Severely

5. To what extent has your family member's disability affected his/her PHYSICAL development (the ability to move around or do things without the physical assistance of others)?
   ____ (1) Not at all ____ (3) Moderately
   ____ (2) Mildly ____ (4) Severely

6. To what extent does your family member's disability require SPECIALIZED MEDICAL ATTENTION (use of specialized procedures, equipment, use of monitoring devices, and/or attention of health care professional)?
   ____ (1) Never
   ____ (2) Occasionally (1 - 6 times a year)
   ____ (3) Monthly
   ____ (4) Weekly
   ____ (5) At least once a day
   ____ (6) Constant/Hourly

7. How often does your family member behave in a way that poses a considerable problem for you or other family members (e.g. tantrums, breaks things, hits self or others, eats unhealthy thing)?
   ____ (1) Never
   ____ (2) Occasionally (1 - 6 times a year)
   ____ (3) Monthly
   ____ (4) Weekly
   ____ (5) At least once a day
   ____ (6) Constant/Hourly

8. Please indicate the degree of assistance that your family member with a disability requires, in completing each of the following activities, by entering the number corresponding to the degree.
   None - (1) Some - (2) Complete - (3)
   ____ Toileting
   ____ Eating
   ____ Bathing
   ____ Grooming
   ____ Dressing
   ____ Communicating Needs
   ____ Movement within home
   ____ Travel out of home

9. How many hours a week is your family member with a disability involved outside the home in each of the following activities?
   ____ Educational hours
   ____ Vocational hours
   ____ Recreational hours (include formal recreation programs AND general recreation with friends, etc.)

ABOUT YOUR FAMILY

10. Indicate which of the following describes your household (check more than one if applicable).
    ____ (1) Two parents in the home
    ____ (2) Single parent household
    ____ (3) Living with relatives
    ____ (4) Foster home
    ____ (5) Shared household with persons other than family
    ____ (6) Other: _____

11. Who is primarily responsible for caring for the family member with a disability?
    ____ (1) Mother
    ____ (2) Father
    ____ (3) Sister/Brother
    ____ (4) Aunt/Uncle
    ____ (5) Grandparent
    ____ (6) Other (Please Specify)_____

RESPITE CARE SURVEY

12. What is the total number of people living in your household? ____
How many are under 18 years of age? ____

13. What is the highest level of education completed by:
a. The primary care giver?
____ (1) Grade 8
____ (2) High school
____ (3) Some college
____ (4) College
____ (5) Graduate school
____ (6) Advanced degree
b. Other adult member of the household?
____ (1) Grade 8
____ (2) High school
____ (3) Some college
____ (4) College
____ (5) Graduate school
____ (6) Advanced degree

14. How many members of the household are employed outside the home
a. On a FULL time basis: ____
b. On a PART time basis: ____

15. In order to take care of your family member with a disability has anyone in your household:
a. Given up a paying job?
____ (1) YES ____ (2) NO
b. Not pursued paid employment?
____ (1) YES ____ (2) NO
c. Refused a job transfer or promotion?
____ (1) YES ____ (2) NO
d. Changed jobs for better benefits?
____ (1) YES ____ (2) NO
e. Changed jobs for different hours?
____ (1) YES ____ (2) NO
f. Not pursued further educational goals?
____ (1) YES ____ (2) NO

16. What was the TOTAL taxable family income last year (1987)?
____ (1) $0-$9,999
____ (2) $10,000-$19,999
____ (3) $20,000-$29,999
____ (4) $30,000-$39,999
____ (5) $40,000-$49,999
____ (6) $50,000- $75,000
____ (7) $75,000 or more

AVAILABLE RESPITE AND YOUR USE OF RESPITE SUPPORTS

17. Have you used respite service in the past year?
____ (1) YES ____ (2) NO (If NO, Skip To #41)

18. In the past year, have you received respite care from a source at least partially subsidized by public funds?
____ (1) YES ____ (2) NO (If NO, Skip To #22)

19. How many hours of respite are you allocated a month from the respite service?
_____ Hours
____ (1) As many as needed____ (2) Don't know

20. When you use a publicly supported in-home respite service, who selects the person who comes to your home?
____ (1) I select the individual of my choice.
____ (2) I select an individual from a list supplied by the agency.
____ (3) The agency selects the individual for me.
____ (4) The agency selects the individual with me.

21. Do you feel that the persons you have used through the publicly supported agency are well qualified?
____ (1) They are not qualified at all.
____ (2) They are poorly qualified.
____ (3) They are just barely qualified.
____ (4) They are well qualified.
____ (5) They are highly qualified.

22. When a respite provider comes into your home will he/she care for the other children in the home?
____ (1) YES ____ (2) NO

23. Are you required to pay additionally for care of the other children in the household either to the respite provider or by hiring another sitter?
____ (1) YES ____ (2) NO
If YES, at what rate: $_____ per hour

24. Use the table below to indicate, in column 1, what type(s) of respite is available in your community and, in column 2, how many hours of each type of respite you have actually used IN THE PAST MONTH.

Check (√)	Hours	
		a. IN-HOME:
____	_____	(1) Family, friends or neighbors
____	_____	(2) By a trained respite professional
____	_____	(3) By a licensed practical nurse
____	_____	(4) Through a formal respite agency
____	_____	(5) Other persons employed in your home
____	_____	(6) OTHER:_____
		b. OUT-OF-HOME:
____	_____	(7) Family, friends or neighbors
____	_____	(8) Private individual's home
____	_____	(9) Respite house or center
____	_____	(10) Space in a local group home
____	_____	(11) Space in an institution
____	_____	(12) Community day care provider
____	_____	(13) OTHER: _____

RESPITE CARE SURVEY

25. What is the contracted rate of pay for publicly supported respite in your area?
$_____ per hour ____ (2) Don't Know

26. For respite that was publically supported, how much did you spend out of pocket in the last month?
$_____

27. What was the hourly rate for respite that you paid for completely on your own?
$_____ per hour

28. How many more hours of respite could you have used in the last month?
____ More hours of IN-HOME respite
____ More hours of OUT-OF-HOME respite

29. Of the types of respite that are currently NOT available in your community, what forms of respite would you like to see implemented?
a. IN-HOME:
____ (1) Family, friends or neighbors with a portion of cost covered by public funds
____ (2) By a trained respite provider
____ (3) By a licensed practical nurse
____ (4) Other persons employed in your house
____ (5) Through a formal respite agency
b. OUT-OF-HOME:
____ (6) Family, friends or neighbors with a portion of the cost covered by public funds
____ (7) Private individual's home
____ (8) Respite house or center
____ (9) Space in a local group home
____ (10) Space in an institution
____ (11) Community day care provider
____ (12) OTHER: _____

30. If the types of respite you indicated in the previous question were available would you make greater use of respite?
____ (1) YES ____ (2) NO

31. For what reason(s) do you use respite? (check all that apply)
____ (1) Relief from the emotional stress
____ (2) To allow me to work outside the home
____ (3) To provide me with time to complete household routines
____ (4) To provide others in the family with time and attention
____ (5) Short term help before school or after school hours
____ (6) To allow time for entertainment or socializing
____ (7) Vacations
____ (8) To give the person with disabilities a chance to be with others or to receive special training
____ (9) Emergencies
____ (10) Illness in the family
____ (11) Other: _____

YOUR SATISFACTION WITH RESPITE SERVICES

32. How far in advance are you expected to schedule respite?
____ (1) Same day as I need it
____ (2) One to three days in advance
____ (3) Four days to a week in advance
____ (4) One to two weeks in advance
____ (5) Over two weeks in advance

33. Does the time in advance you are expected to schedule respite meet your needs?
____ (1) Not at all
____ (2) Some of the time
____ (3) On the average, yes
____ (4) Most of the time
____ (5) All of the time

34. Are you satisfied with the quality of respite you use?
____ (1) Never satisfied
____ (2) Satisfied some of the time
____ (3) Satisfied on average
____ (4) Satisfied mostly
____ (5) Always satisfied

35. When you have emergency situations where you need respite, can you get it quickly enough to meet your needs?
____ (1) Never
____ (2) Only sometime
____ (3) On the average, yes
____ (4) Most of the time
____ (5) All of the time
____ (6) I have never needed emergency respite

36. Do you feel that respite makes a significant difference in your ability to care for a child/adult with disabilities at home?
____ (1) No significance
____ (2) Minor significance
____ (3) Some significance
____ (4) Considerable significance
____ (5) Great significance

37. If you could not receive respite, would you need to consider an out-of-home placement for your child/adult with disabilities?
____ (1) YES ____ (2) NO

38. Do you feel that the opinions of parents are given adequate consideration in planning respite and other services in your community?
____ (1) YES ____ (2) NO

39. Do you feel that you have adequate control over respite and other services that effect your family's life and the life of your family member with a disability?
____ (1) YES ____ (2) NO

PROBLEMS YOU HAVE ENCOUNTERED WITH RESPITE

40. Have you encountered any of the following obstacles to using publicly supported respite (check all that apply)?
____ (1) No publicly supported respite in my area
____ (2) Didn't know where to go to get help
____ (3) Waiting list was too long
____ (4) Didn't have enough time to make arrangements
____ (5) Family member with disabilities has/had a problem for which no care was available
____ (6) Not satisfied with the quality of care available
____ (7) Reluctant to leave child/adult with a stranger
____ (8) Couldn't afford it
____ (9) Child/adult was too upset or refused to cooperate
___ (10) Lack of transportation
___ (11) Family didn't qualify for the support
___ (12) Not enough respite allocated to meet our needs
___ (13) The need to pay additionally for the care of other children in the household
___ (14) Available forms of respite are not appropriate for my family member
___ (15) OTHER: _____

CHANGING THE RESPITE SYSTEM IN YOUR COMMUNITY

41. How optimistic are you that the family supports, including respite, available in your community will be changed for the better over the next few years?
____ (1) Not at all optimistic
____ (2) Somewhat optimistic
____ (4) Optimistic
____ (5) Very optimistic

42. If you were to try to change things in your community, by either helping to start a respite system or to improve the one(s) already in operation, please rate the types of information you would need by circling the number from 1 - 5 that most reflects your need.

The higher the number you circle, the greater is the need.

POTENTIAL INFORMATION

	LOW				HIGH
a. Various respite alternatives.	1	2	3	4	5
b. Existing model respite programs.	1	2	3	4	5
c. Documentation showing that respite is a help to families.	1	2	3	4	5
d. People to call who run model systems.	1	2	3	4	5
e. Potential sources of funding.	1	2	3	4	5
f. Methods of recruiting, training and supervising respite providers.	1	2	3	4	5
g. Information on how to evaluate services.	1	2	3	4	5
h. Information on how to work with respite and other service providers.	1	2	3	4	5
i. Learning how to discover what family supports are already available to me.	1	2	3	4	5
j. Learning how to get into contact with other families like mine.	1	2	3	4	5
k. Learning how to organize other families and others who want to help change things.	1	2	3	4	5
l. Understanding who to contact to initiate change.	1	2	3	4	5
m. Learning how to advocate for and facilitate change.	1	2	3	4	5

RESPITE CARE SURVEY

YOUR GREATEST NEEDS

43. In providing you with information you need, indicate three (3) of the following formats you would most prefer. Please rank your choices 1 (most preferred) through 3.
____ (1) A single volume containing all the information.
____ (2) A series of pamphlets, each specializing on one topic.
____ (3) A monthly newsletter, broadly focused on the topic of family supports, with each issue focusing on a particular topic such as respite, supported work, school integration, residential services, etc.
____ (4) Videotape on respite that could be obtained through *Exceptional Parent*.
____ (5) A regular column on family support issues in *Exceptional Parent* magazine.
____ (6) Periodic articles printed in *Exceptional Parent* magazine, with each highlighting a particular topic.
____ (7) A national or statewide toll-free hotline with information about respite and other family support services.
____ (8) A package of training and reference materials (e.g., Videotapes, reprints of articles, workshop agendas) which could be purchased and used by a local parent training group or advocacy organization.

44. If items 1 through 4 in the previous question were available, would you purchase them?
___(1) YES ____(2) NO
(If YES, how much would you be willing to spend for each item?
$_____(1) A single volume containing all the information.
$_____(2) A series of pamphlets, each specializing on one topic.
$_____(3) A monthly newsletter, broadly focused on the topic of family supports, with each issue focusing on a particular topic such as respite, supported work, school integration, residential services, etc.
$_____(4) Videotape on respite that could be obtained through *Exceptional Parent*.

45. Indicate the level of need you have for the following types of support by circling a number from 1 to 5 for each that most reflects your need. *The higher the number you circle, the greater your need.*

POTENTIAL NEED	LOW				HIGH
a. Information on disability or where/how to obtain services.	1	2	3	4	5
b. Help with assuring the FUTURE well-being of our family member with disabilities.	1	2	3	4	5
c. Temporary IN-HOME relief or respite.	1	2	3	4	5
d. Temporary OUT-OF-HOME relief or respite.	1	2	3	4	5
e. Financial assistance to help pay for the special needs of our family member with disabilities.	1	2	3	4	5
f. Supports for the ENTIRE FAMILY or OTHER FAMILY MEMBERS (sibling counseling, homemaker services, day care).	1	2	3	4	5
g. Adequate health care (e.g. health insurance) for our family member with disabilities.	1	2	3	4	5
h. A daytime program for our family member with disabilities.	1	2	3	4	5
i. Specialized services for our family member with disabilities (transportation, recreation, physical/language therapies)	1	2	3	4	5

POTENTIAL FUTURE CONTACT

46. Later in the project we may want to speak directly with a sample of persons who completed this questionaire. If you are willing to be one such person, please print your name, address and phone number in the space below.
Please print: Name_____
Address_____
City_____State_____Zip_____
Phone Number_____

THANK YOU FOR YOUR TIME!!! PLEASE BE SURE TO MAIL YOUR COMPLETED FORM BACK TO US IN THE ATTACHED PRE-ADDRESSED AND PRE-PAID ENVELOPE or mail to:
RESPITE CARE SURVEY, *Exceptional Parent* Magazine, P. O. Box 657, Kenmore Station, Boston, MA 02215

END

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